

A thesis submitted as requirement of the Clinical Psychology Doctorate:

VOLUME I: RESEARCH

**THE CONTINUED IMPACT OF YOUNG ONSET DEMENTIA ON
DEPENDENT CHILDREN AS THEY MAKE THE TRANSITION INTO
ADULTHOOD –**

A FOLLOW UP STUDY TO ALLEN, OYEBODE AND ALLEN (2009)

By

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September 10th 2010

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To Darran

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OVERVIEW OF THESIS

To fulfil the requirement of the Clinical Psychology Doctorate (Clin.Psy.D) at the University of Birmingham, a Research Volume and a Clinical Volume are submitted.

All information has been anonymised for confidentiality purposes.

Volume I comprises the research component and includes the Empirical Paper, Literature Review and Public Domain Paper. The literature review considers what is already known about how individuals respond to loss over the dementia journey including death. The quality of the papers is assessed and remarked upon. The literature review will be submitted to the Journal of Aging and Mental Health. The Empirical Paper is a continuation study of young people's experiences of having a father with young onset dementia. A Grounded Theory model of their experiences over the illness journey is presented. The paper will be submitted to the Dementia: The International Journal of Social Research and Practice. The Public Domain Paper gives a brief overview of the empirical paper and the literature review. The final section comprises the Appendices. Tables and figures are embedded within the text

Volume II comprises the clinical component. Five Clinical Practice Reports are included. The first paper presents a Systemic and Cognitive Behavioural formulation of a female with learning disabilities who was experiencing low self-esteem. The second report is a service evaluation which explored carer's perceptions of the quality of a local residential unit which they accessed. Quality was compared with national standards for children with profound and multiple learning disabilities. Recommendations for change and improvement were given. The third paper is a case study detailing the assessment, formulation, intervention and evaluation of a young male who was experiencing low self-esteem. A single case study is the fourth paper and outlines an innovative attachment based approach to addressing separation distress in an older adult housed on a continuing needs ward for dementia. The final report is an abstract for a presentation of a four year old girl who was referred for hair pulling behaviour. Assessment indicated the parents were not attuned to the child's needs and the author outlined the formulation and intervention using the Solihull Approach. Appendices are available at the end of each report. Tables and Figures are embedded within the text.

LITERATURE REVIEW

**LOSS AND GRIEF IN THE LIVES OF CAREGIVERS OF PEOPLE WITH
DEMENTIA: A REVIEW**

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Abstract

The following literature review considers the quality and findings of studies which have explored loss and grief responses in informal caregivers over the course of caring for a person with dementia up to and including their death. Papers were critiqued using quality criteria drawn up by the author based on the Critical Appraisal Skills Programme and relevant literature. All papers except one were of at least satisfactory quality and were included in the review. Research suggests that relatives experience multiple losses and grief over the course of caring for someone with dementia; with some differences between men and women, and between adult-child and spouse caregivers. Stage of disease and transitions have also been found to affect caregivers' grief responses whilst ambiguity makes it difficult for caregivers to understand their grief. Throughout the course of looking after a relative with dementia, particular events are more likely to trigger a grief reaction; for example, spouses have been found to experience high levels of distress when their partner is placed into a carehome. Grieving prior to death appears to be more akin to "true grief" rather than anticipatory grieving. A number of interventions and indicators for future research are offered.

Keywords: caregiving, dementia, grief

Introduction

Our understanding of caregiver burden and stress within dementia is considerable (Sanders, Ott, Kelber & Noonan, 2008; Ott, Sanders, & Kelber, 2007), with research looking into the impact of burden on emotional, physical and mental health (Noyes et al., 2009). However, since the mid 1990s, attention has turned to the grief and losses which are experienced over the dementia journey, including death of the care recipient, as clinicians and researchers suggest caregiver wellbeing is also affected by grief. Some researchers suggest that grief explanations challenge the dominant Stress-Burden Model and offer alternative perspectives about how caregivers respond, grow and make meaning of their situation (Noyes et al., 2009; Meuser & Marwit, 2001). By exploring grief in addition to stress, it is suggested a fuller picture of the experiences of dementia caregivers is given (Butcher, Holkup & Buckwater, 2001; Holley & Mast 2009). A connection between the two areas has been suggested by Bass & Bowman (1990 as cited in Sanders & Corley, 2003) who found that caregiving stress and burden in dementia were significant predictors of grief and bereavement strain. Further evidence is provided by Collins, Liken, King & Kokinakis (1993) who state that “family caregiving and bereavement, often treated as separate events are in fact, part of a single chronic situation” (p.238 as cited in Sanders and Adams 2005).

Reviewing the literature on grief responses within caregiving for a relative with dementia comes at a pertinent time as dementia is on the increase and Alzheimer’s disease and related dementias are the fifth leading cause of death among the over 65s (DoH, 2009; Centre for Disease and Control Prevention, 2004 as cited in Sanders, Butcher, Swails & Power, 2009). The literature highlights the lack of recognition from professionals about the impact of grief on wellbeing in caregivers (Sanders, Marwit, Meuser and Harrington, 2007). However the bereavement literature indicates that individuals who experience intense and prolonged grief symptoms such as yearning, diminished sense of self and trouble accepting the loss are at a higher risk of physical and mental health consequences (Sanders, Marwit, Meuser and Harrington, 2007; Sanders, Ott, Kelber & Noonan, 2008). This is important when relatives may be caring for individuals with dementia for up to 20 years (Sanders et al., 2008). Gaining a better understanding of caregivers’ grief responses over the illness trajectory and death will lead to better, more timely interventions.

Method of the Review

Studies referring to both “loss” and “grief” were included in this review. Grief was defined as the “caregiver’s expression of their loss” whilst loss encompassed the number and types of losses that the caregiver experiences over the dementia journey which can trigger a grief response. All the articles were required to contain a discussion on how caregivers respond to losses within dementia caregiving. For qualitative papers, the analysis had to be exploring grief or loss experienced by caregivers of people with dementia, whilst quantitative papers had to include a measure of caregiver grief or loss.

In addition, the following inclusion and exclusion criteria provided the parameters of the search for relevant papers.

Inclusion criteria:

1. All terms related to dementia were included e.g. Alzheimer’s, dementia
2. All terms related to loss were included e.g. ambiguous loss
3. All terms related to grief were included e.g. anticipatory, complicated, disenfranchised
4. All stages of the dementia journey were considered e.g. mild cognitive impairment, early/mild, middle, late and death
5. Qualitative, quantitative and mixed methods papers were all considered
6. All articles had to be published in peer reviewed journals

Exclusion criteria:

1. All articles relating to dementia or grief separately
2. All articles before 2000, since earlier studies of grief tend to focus on the objects rather than the processes of loss (Ott, Sanders, & Kelber, 2007).
3. Papers which did not specifically address the nature of loss/grief responses in caregivers, e.g. review of an psycho-educational group for grief and loss in dementia
4. Any article exploring young onset dementia as studies have found that the needs and experiences of families with a person with young onset dementia are qualitatively

different from those who develop dementia in later life (Kaiser & Panegyres, 2007; Beattie, Daker-White, Gilliard, & Means, 2002)

5. Young people and children's grief responses to caregiving

Papers were obtained using a number of strategies. Initially, the PsycInfo database was used to search for papers. Initial keywords included: dementia, loss, grief and caregiver. Entering "grief AND dementia AND caregiver" into the "keyword" option between "2000 and current" on PsycInfo yielded 70 results. Review of abstracts identified 16 possible papers. Ten papers were accepted as they met the inclusion criteria. Subsequently, all references from included papers were reviewed. This yielded five results. Author searches were conducted on prominent names within the literature: Sanders; Marwit; Meuser. Two further results were obtained. Finally a Google search using the keywords "loss, grief, dementia and 'after 2000'" produced the final result. A number of papers appeared to meet the inclusion criteria however were excluded after reading the paper (not included in numbers above). These are commented on within the limitations of the study.

Overview of Studies Reviewed

In total 17 papers were included in the review, representing reports on nine different research samples.

Tables 1 and 2 summarise the quantitative studies and qualitative studies respectively. The majority of the studies recruited caregivers through purposive sampling (convenience sampling with selectivity) such as the local chapter of their Alzheimer's Association, memory clinics or word of mouth. Adams & Sanders (2004) and Frank (2007) also used random sampling of the community database of a chapter of the Alzheimer's Association before convenience sampling. Two studies, which were part of the larger REACH study, obtained participants through a randomised control trial of 6 multi-site interventions (Schulz, Boerner, Shear, Zhang, Gitlin, 2006; Boerner, Schulz & Horowitz, 2004). Except for two Canadian studies (Silverberg, 2007; Dupuis, 2002) and one UK study (Robinson, Clare & Evans, 2005), the remaining studies were American. It is noted that the American and Canadian studies in care homes (Dupuis, 2002) may include individuals with mild dementia, something which is not typically found in UK care homes. Studies varied in sample size from 4 (Silverberg, 2007) to 353 caregiver responses (Frank, 2007). The majority of sampled caregivers were Caucasian

women, either adult daughters or wives; one study explored male caregivers (Sanders, Morano & Corley, 2002) and one study explored cultural differences between “White” and African American families (Owen, Goode & Haley, 2001). All except three studies (Dupuis, 2002; Robinson et al., 2005; Blieszner, Roberto, Wilcox, Barham & Winston, 2007), included both adult children and spouses and considered the differences between these groups. However, seven of these studies also had unknown or other family members/friends included in the sample. Furthermore, Schulz et al., (2006) and Boerner et al., (2004) did not state the number of adult children in their study. In two of Sanders and colleagues’ samples, spouses are less represented than adult children (Sanders, Butcher, Swails & Power, 2009; Adams & Sanders, 2004) and therefore the reader should be more cautious about their conclusion that there are no differences between spouses and adult children as found in Marwit and Meuser’s larger study on caregivers (2001;2002;2005). Moreover, Marwit and Meuser’s conclusions are based on caregiver focus groups data whilst Adams and Sanders is drawn from caregiver written responses to an open-ended question at the end of a postal survey.

Quality Criteria

To enable consideration of the quality of the papers, quality criteria tables were drawn up based on the Critical Appraisal Skills Programme (CASP, 2009) and relevant literature (Aveyard, 2007; CASP, 2009; Kuper, Lingard, Levinson, 2008; McQueen & Knussen, 2002; Robson, 1993; See Table 3 for Quantitative Quality Criteria and Table 4 for Qualitative Quality Criteria). Mixed method papers have been appraised in both tables (indicated by an *). Scores from 0-2 were assigned to each study for each indicator of quality and totals were calculated to guide the reader on the quality of the paper. A score of 0 is poor, 1 is satisfactory and 2 indicates that the paper has met most of the criteria.

Whilst it is admitted that there is a subjective element to this appraisal, it gives an overall guide to the quality of the research. Generally greater weight should be given to those studies that met more of the quality criteria. The key themes arising from this quality appraisal are presented below, with particularly significant flaws in quality highlighted. A review and synthesis of the key findings of the studies follows.

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
Adams and Sanders 2004*	Caregiver difference (spouse/ adult children) in experience of loss, grief reactions and depressive symptoms across stage of disease	All stages (locations were analysed)	99 caregivers across disease stages (bereaved caregivers not included) (49 adult children/ 35 spouses; 24 early/ 41 middle/ 33 late phases of dementia)	Random selection of caregivers of local AD Chapter Written responses to two questions were analysed using open coding and comparisons to identify themes (reference Strauss & Corbin, 1990) 1. Are you currently grieving the loss of your loved one even though s/he is still alive? Explain 2. Please define the greatest areas of loss you have experienced as a result of the loved ones illness and your caregiving role.	59% of sample indicated they were grieving although care recipient still alive. Losses identified over the 3 stages: 1. Future losses and missed shared activities. hopeful; do not acknowledge loss 2. Burden and loss of personal freedom 3. Loss of person and like a bereavement	Caregiving in the late stages of dementia reported more grief and resembled bereavement. Different grieving and processing dependent on stage of disease.
Blieszner, Roberto, Wilcox, Barham and Winston 2007	Ambiguous Loss in couples coping with Mild Cognitive Impairment (MCI)	Mild cognitive impairment / home	67 married couples with a partner with a diagnosis of MCI	Interview with both person with MCI and spouse. Research members took transcripts and developed 1 page synopsis which were analysed by the whole team. Analysed using Grounded	3 main themes: 1. Ambiguity around symptoms and diagnosis 2. Distress resulting from ambiguous loss following MCI	Ambiguous Loss occurs in very early stages of memory changes as it unclear if there is a problem (vague and

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
				Theory and managed using ATLAS.	diagnosis 3. Resilience in partner following MCI diagnosis	unpredictable) and unknown future trajectory. Spouses have become “care partners”. Resilience decreases distress caused by ambiguous loss.
Dupuis 2002	Adult children’s perspectives of Ambiguous Loss in care facilities over the 3 defined stages of dementia (within a carehome) * note Canadian carehomes	Care facility	61 adult children who have a parent with dementia in a care facility	Part of a larger study. In-depth active interviews using an interview guide (adapted through interviews), transcribed, authors comments and checked by participants. Used Symbolic Interactionism and the conceptual framework of the caregiving career as underlying framework. Grounded theory methodology	Progresses through phases which match the stage (within carehome) however this is more about the person’s perception rather than length of time in role 1. Anticipatory 2. Progressive 3. Acknowledged Coping strategies: Acceptance Avoidance	Adult children live through ambiguous loss, it is not stable. It begins early and carries on throughout career. Ambiguous loss occurs across suggested phases which appear to map onto the stages of dementia in care facilities. Avoidance associated with higher levels of

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						distress
Frank 2007	Grief as a major barrier to caregiving specifically Anticipatory grief and Ambiguous Loss	All stages (not given) / all locations (62% community/ 27% carehome)	353 responses from spouses (38%), adult children (53%) or other (9%) currently caring for a person with dementia or whose relative had died within last 6 months (4.5%)	Part of a larger study addressing emotional needs of caregivers. 353 responses to one of 3 qualitative questions at the end of a postal survey “what is the biggest barrier you have faced as a caregiver?” obtained through random sample (34%) of Alzheimer’s Association and convenience (66%) sampling through events etc Analysed through Nvivo, no research methodology approach given.	75% responses related to anticipatory grief 5 main themes: 1. Caregiver role versus personal life 2. Patient related challenges due to disease 3. Personal grief and loss 4. Lack of support 5. Communication	Main themes map onto the MM-CGI. This suggests grief is biggest barrier to caregiving. Anticipatory grief, disenfranchised grief and ambiguous loss are experienced throughout the dementia journey and are more important than care tasks. Suggests support for Dupuis (2007) ambiguous loss in spouses as well as adult children but didn’t state whether explored or categorised stages of illness. Also suggests differences for

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						spouses and adult children but not clearly defined in study.
Meuser and Marwit 2001*	To develop a model of grief in dementia caregiving	All stages and post death/ all locations (not differentiated by location)	87 spouse and adult child caregivers across the stages and postdeath (42 spouses/45 adult children)	16 focus groups (8spouses/8 adult children) ranging from 2 -9 people. 14 had over 5. Stage of dementia obtained through postal GAQ with a CDR informant interview included. Semi-structured interview. Teams reviewed up to 3 videos and made narratives with illustrations. Main themes complied together for each stage/caregiver type.	<ol style="list-style-type: none"> 1. Adult children and spouses grief process is different from each other 2. For both, there is discernable differences at each stage (Stages already pre-determined by CDR) 	<p>Anticipatory Grief experienced in dementia is more akin to “real” grief post death.</p> <p>Nursing home placement is significant for both groups but triggering a grief response for spouses.</p> <p>Adult children experience is curvilinear, whilst spouses are linear.</p> <p>Adult children shift from self to other. Spouses shift from other/conjoint to self.</p>

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						Multiple factors influence grief in caregivers.
Robinson, Clare and Evans, 2005	Exploring psychological responses to loss in couples given a diagnosis of dementia	Couples where a person had received diagnosis of a dementia within the past 2 years with early or mild stage dementia (mean 11 months)	9 married couples Recruited from 4 memory clinics and out-patient psychiatry departments.(five women and four men with dementia)	<p>Joint interview at home with each couple.</p> <p>Transcripts analysed through IPA by all 3 researchers</p> <p>Triangulation; member validation; internal coherence ensured through multiple measures including consulting participants</p> <p>Acknowledged influenced by existing literature</p>	<p>10 themes within 2 higher order themes:</p> <ol style="list-style-type: none"> 1. Not quite the same person, tell me what is actually wrong 2. Everything's changed, we have to go from there <p>Overarching theme: Making sense and adjusting to loss</p>	<p>Making sense and adjusting to loss after a diagnosis is comparable with dual-process models of grief.</p> <p>Acknowledging the losses inherent in dementia was key for both partner and person with dementia. However some struggled with this.</p> <p>Appears that accepting diagnosis may facilitate adjustment to differences in</p>

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						person with dementia (although not clear relationship).
Sanders, Butcher, Swails and Power 2009	To explore caregiver's grief responses who were accessing hospice care	Late stage (end of life)/hospice	27 family caregivers taken from 2 hospices (13/14) (20 female/ 7 male; 25 nursing home/ 2 home; 4 spouses, 22 adult children, 1 grandchild)	Part of a larger project on hospice care and late stage dementia. Ethnomethodology, interviews, tape recorded and transcribed (4 telephone interviews, detailed notes taken rather than transcribed) over 10 months. Qnivo analysed. Independent qualitative researcher to improve trustworthiness of results	4 main themes: 1. Disengaged caregiver (n=5) 2. Questioning caregiver (n=8) 3. All consumed caregiver (n=10) 4. Reconciled caregiver (n=4)	Caregivers approach end of life care and death in diverse ways which they appear to stay in during the course of the end stages. This may be due to social (stigma stopping assistance to address issue) or personal factors (coping strategies). Higher grief responses were found in questioning and all consumed caregivers.

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						Disengaged caregivers may be at risk of complicated grief reactions as some may not have addressed unresolved conflict with relative
Sanders and Corley 2003	Examining what caregivers report contribute to whether they are grieving or not grieving when caring for an individual with AD	All stages/ all locations	Part of a larger study 253 caregivers (41% spouse, 46% adult child, 13% other; male 28%, female 69% did not respond, 2% also stage of disease and location of care given) Obtained from Alzheimer's Association	Postal survey and asked to answer the following qualitative question: "do you believe that you are grieving the loss of your loved one even though s/he is still alive?" explain. Reponses were divided into grieving/ not grieving. Data analysed using Padgett's (1998) recommendations	2 main themes: 1. Not grieving (n= 80) ▪ Relief (time/strengths) ▪ Religion and spirituality ▪ Previous relationship (conflict) 2. Grieving (n=173) ▪ Ambiguity ▪ Loss of previously established roles ▪ Loss of intimacy ▪ Feelings of	Evidence of loss found in both non/grieving statements and the non-grievors accounts reflect elements of the grief process. Grief is extremely complicated and influenced by multiple factors especially the ambiguous loss associated with dementia. This

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
					<p>desperateness and loss of control</p> <ul style="list-style-type: none"> Self awareness of grief 	ambiguity may make the grieving process even more difficult. Social stigma (disenfranchised grief) may stop caregivers from stating grieving.
Sanders, Morano and Corley 2002	Loss and grief in male caregivers	All stages/ all locations	<p>Part of a larger study.</p> <p>71 male caregivers (26% of sample – 253 caregivers) who are currently caring for a person with dementia</p>	<p>Postal survey and asked to answer the following qualitative question: “do you believe that you are grieving the loss of your loved one even though s/he is still alive?” explain.</p> <p>Male responses were taken from larger sample.</p> <p>Data analysed through Padgett (1998). Data was peer reviewed and debriefed</p>	<p>2 main themes:</p> <ol style="list-style-type: none"> Grieving (n=48) <ul style="list-style-type: none"> Grief turned into crisis (n=16) Self awareness and insight into losses and grief journey (n=32) Non-grieving (n=23) <ul style="list-style-type: none"> Emotional dissociation from the care recipient (n=13) Life could be worse (n=10) 	Males experience loss reactions as well as females which are expressed differently. Their emotional reaction can be intense and female coping strategies may not be affective for males or they may not access them e.g. support. Complicated and not consistent with a number of

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
						factors identified. Men in crisis group had thoughts of harm (killing self/spouse) due to loss. different intervention for males needed
Sanders, Ott, Kelber and Noonan, 2008*	Experience of high levels of grief in caregivers of persons with ADRD and impact on health	Those identified with high grief selected as sample population	Part of a larger study (Ott, Sanders, & Kelber, 2007). 44 spouses and adult children who scored high on the MMCGI (equal spouses and adult children)	Mixed methods study (questionnaire and Interview) Semi-structured interview (areas given) Data analysed through Padgett (1998) and Constant Comparative Method	7 main themes for those experiencing high grief (all caregivers): 1. Yearning for the past (n=31) 2. Regret and guilt (n=26) 3. Isolation (n=20) 4. Restricted freedom (n=19) 5. Life stressors (n=19) 6. Systemic issues (n=11) 7. Coping strategies (n=15)	Possible grief profile for caregivers with potentially differences in the themes for adult children and spouses. Spouses yearn more for the past, feel isolated, restricted freedom, have other life stressors and have various forms of coping strategies. Adult children

Table 1: Overview of qualitative Studies

Author	Purpose of study	Stage / location	Participants	Methodology	Main Themes	Grief responses identified
					Differences in adult children and spousal themes	express guilt and regret and care is hindered by services. Multiple factors influence grief in caregivers.
Silverberg 2007	Introduction of a model of intervention for grief in dementia caregiving	Care facility	Author, 4 informal caregivers, Previous accounts from literature (numbers not given)	Interpretative approach Review of the current literature, personal experience and analysis using Grounded theory with interviews of 4 informal caregivers (one husband, two wives and one adult son). All patients were in nursing home/awaiting placement. Also gave accounts from the literature to back claim	Description of model: 1. Acknowledging different types of grief 2. Assessing what grief experienced 3. Assisting	Grief is a continuous process which passes through the suggested phases. Caregivers may express grief either intuitively (feeling) or instrumentally (doing). Those who express instrumentally are harder to identify

* - indicates studies which have used a Mixed Methods

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
Adams and Sanders 2004*	Examined caregiver difference in experience of loss, grief reactions and depressive symptoms across stage of disease	99 caregivers across disease stages (bereaved caregivers not included) (49 adult children / 35 spouses; 24 early/ 41 middle/ 33 late phases of dementia)	Postal survey	<ul style="list-style-type: none"> Marwit-Meuser Caregiver Grief Inventory (MM-CGI) 	<ul style="list-style-type: none"> Geriatric Depression Scale (GDS) Problematic Behaviours Scale (PBL) 	<ul style="list-style-type: none"> ANOVA and cross tabulations (initial analysis) Descriptive stats MANOVA Post hoc univariate t-tests 	<p>Descriptive stats: late stage had “at risk” problematic grief reaction (Mean total score 169.93) and depression (15.9; cut off 11)</p> <p>MMCGI scores and all 3 subscales are higher for late stage group than early (HSL = $p = .001$) middle groups (WFI = $p = .001$, HSL = $p = .01$ and PSB = $p = .024$).</p> <p>Higher than on norms by Marwit and Meuser (2002) which were significant especially on aspects of post bereavement grief</p> <p>Stage is most prominent indicator to grief experienced</p> <p>Relationship status was not significant (differs from Meuser & Marwit, 2001) but maybe insufficient power.</p>

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
							However suggest stage is more important than relationship
Boerner, Schulz and Horowitz 2004	Exploring positive aspects of caregiving and adaption to bereavement (included depression)	217 bereaved in – home caregivers	Questionnaire data taken year before and after bereavement as part of wider REACH study	<ul style="list-style-type: none"> ▪ Texas Revised Inventory of Grief (alpha =.87) 	<ul style="list-style-type: none"> ▪ Centre for Epidemiological Studies Depression Scale (alpha .74) ▪ Caregiving benefit is an adapted scale from the Caregiver Health Effects Study (alpha = .91) ▪ The Index of ADLs – (alpha = .96) ▪ Revised Memory and behaviour problem checklist (alpha=.86) 	<ul style="list-style-type: none"> ▪ Multivariate analyses ▪ Blockwise hierarchical analyses 	<p>20% of variance accounted for by caregiving benefit.</p> <p>Caregiving benefit significant positively linked with higher grief scores postloss and therefore suggested could be used as predictor of grief (.47 at $p < .001$).</p> <p>Relationship type is an independent predictor. Spouse are more likely to report higher levels of grief postloss (.31. $p < .001$)</p>

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
Holley and Mast 2009	Impact of Anticipatory Grief (AG) on caregiver burden	80 informal caregivers (mild, moderate and severe dementia; 21 spouse/49 adult children/ 10 other)	Questionnaire by interview	<ul style="list-style-type: none"> Marwit-Meuser Caregiver Grief Inventory (total score alpha = .96) Anticipatory Grief Scale (alpha = .89) 	<ul style="list-style-type: none"> The revised memory and behaviour problems checklist (.84 patient behaviour/ .90 caregiver reaction) Geriatric Depression Scale (alpha =.83) Zarit Burden Interview Short form (alpha = .88) Montgomery Burden Inventory (alpha = .86) 	<ul style="list-style-type: none"> Correlations Bivariate Correlations Multiple regression analysis Hierarchical linear regression analysis 	<p>Disease severity was weak and therefore subgroup analyses were dropped.</p> <p>Anticipatory Grieving and caregiver burden were positively correlated (r between .68 and .73) ; with subscale analysis – MM-CGI personal sacrifice and burden having strongest relationship (r = .79 for ZBI, r = .76 for Montgomery at $p < .01$)</p>

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
Meuser and Marwit 2001*	To develop a model of grief within dementia caregiving	87 spouse and adult child caregivers across the stages and postdeath (42 s/45 ac)	Convenience sample, questionnaire though post	<ul style="list-style-type: none"> Anticipatory grief scale Many faces of grief questionnaire 		<ul style="list-style-type: none"> Descriptive statistics, mean difference comparisons correlations 	<p>To assist allocation to correct focus group Similar levels of reported grief</p> <p>Adult children had sig higher scores on jealousy, negativity, questioning meaning of life.</p> <p>Spouses were more lonely and loss of sexual intimacy (not given).</p> <p>Overall grief declines over illness progression which does not reflect qualitative data in study (-0.45, $p < .01$)</p> <p>AGS has inverse correlation with time but not CDR scores or caregiver type (-.276, $p < .05$)</p>
Marwit and Meuser 2002	Development to assess grief in caregivers of persons with AD	166 caregivers (83 adult children and 83 spouses)		<ul style="list-style-type: none"> Anticipatory grief scale (AGS) (alpha = .84) 	<ul style="list-style-type: none"> Beck depression inventory (BDI) (alpha = .86 and .81) 	<ul style="list-style-type: none"> Factor analysis 	<p>Grief is not static therefore scale is beneficial to assist professionals in assessing grief.</p> <p>Development of the Marwit &</p>

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
(given as main scale used for studies assessing grief in dementia caregivers)				<ul style="list-style-type: none"> Caregiver grief items (generated from statements [quotations] made in FG in Meuser & Marwit, 2001) 	community) <ul style="list-style-type: none"> Geriatric Depression Scale (GDS) (alpha = .94 / split-half = .94) Caregiver strain index (alpha = .86) Caregiver well being scale (alpha = .91) Perceived social support family questionnaire (alpha = .74) 		Meuser Caregiver Grief Inventory with 3 subscales: <ol style="list-style-type: none"> 1. Personal sacrifice burden 2. Heartfelt sadness and longing 3. Worry and felt isolation Total score (alpha = .96)
Ott, Sanders, Kelber, 2007	Grief and personal growth experiences of spouses and	201 (90 spouses and 111 adult children)	Convenience sample; questionnaires (Interviews –	<ul style="list-style-type: none"> MMCGI-SF (alpha = 0.915) 	<ul style="list-style-type: none"> The functional assessment staging of dementia 	<ul style="list-style-type: none"> Descriptive stats group t test, 	Grief and personal growth processes are different. Adult children experience more growth than spouses. ($p = .046$)

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
	adult children caregivers		not given in current study)	<ul style="list-style-type: none"> Personal Growth subscale in Hogan Grief reaction checklist (alpha= 0.881) Inventory of social support (Alpha = 0.881) 	<p>scale (FAST)</p> <ul style="list-style-type: none"> Positive states of mind scale (POSM) (Alpha = 0.885) Brief cope inventory (Alpha range = 0.982 – 0.870) CES-D (alpha = 0.889) Revised Dyadic Adjustment scale (alpha = 0.872) 	<ul style="list-style-type: none"> independent chi-square test, Analyses of variance multi-analysis of variance correlations hierarchical regression analysis 	<p>Stage of disease affects grief.($p=.001$)</p> <p>Adult children use substances, venting, reframing and humour more than spouses ($p<.05$)</p> <p>Spouses and adult children respond differently to nursing home placement. Spouses score significantly higher when partner not at home on all 3 subscales (PSB = $p = .022$ WFI = $p = .001$ HSL = $p = .002$)</p> <p>Spouses also report more guilt and sadness whilst adult children report decrease in burden.</p>
Owen, Goode and Haley,	What are the ethnic characteristics	63 bereaved caregivers of community	Part of larger study	<ul style="list-style-type: none"> Caregiver Bereavement Questionnaire 		<ul style="list-style-type: none"> Descriptive statistics 	Reported ethnic differences in end of life care and reactions to death.

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
2001	of African Americans and White Caregivers to end of life care and death in dementia	care recipient (43 white / 16 African-American) mostly women (68.8%)	Questionnaire battery delivered through structured interview. Advised to read earlier studies.	e devised from the Texas Inventory of Grief and the revised version and additional questions		<ul style="list-style-type: none"> ▪ Chi-square analysis (categorical variables) ▪ Between group T-tests (continuous variables) ▪ Multiple regression analyses 	<p>African Americans were less likely to withhold treatment prior to death ($p = 0.002$)</p> <p>Prior to death African Americans were:</p> <ul style="list-style-type: none"> ▪ Less likely to think about doing in the event of death ($p=0.002$) ▪ To grieve ($p=0.01$) ▪ To make funeral plans ($p=0.03$) <p>After death, African Americans were less likely to:</p> <ul style="list-style-type: none"> ▪ Feel relief ($p=0.01$) ▪ To accept death ($p=0.009$)
Sanders and Adams 2005	Grief reactions and depression in caregivers living in an urban setting	99 current caregivers (69 women/30 men; 55		<ul style="list-style-type: none"> ▪ Marwit-Meuser Caregiver Grief Inventory 	<ul style="list-style-type: none"> ▪ Geriatric Depression scale (alpha=.81) 	<ul style="list-style-type: none"> ▪ Multiple regression analysis 	Higher levels of grief found than original Marwit and Meuser study for scale (2002) (mean total score = 155 (SD 30.5).

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
		white, 31 African American, 9 Hispanic, 4 Asian; 46 AC, 35 spouses, 15 other)		(alpha = .94 for total score; .84- .92 subscales)	<ul style="list-style-type: none"> The Problematic Behaviour Scale (alpha = .90) 		<p>There is an inter-relationship between depression and grief</p> <p>Those who experience heartfelt sadness and longing ($B = .270$ $p < .0005$) and personal sacrifice and burden ($B = .213$ $p < .0005$) had higher rates of depression</p> <p>48% of the variance in the GDS explained by grief scores</p> <p>Indicates grief responses need to be included in assessment of caregivers as currently misdiagnosed as depression</p>
Sanders, Ott, Kelber and Noonan, 2008*	Experience of high levels of grief in caregivers of persons with ADRD	44 caregivers who scored high on the MMCGI scale	Part of a larger study. Questionnaire	<ul style="list-style-type: none"> Marwit-Meuser Caregiver Grief Inventory (alpha for scales = 0.78 – 0.84) 	<ul style="list-style-type: none"> Brief Cope Hogan Grief Checklist Demographic and care related information 	<ul style="list-style-type: none"> Did not state in paper (chi-square and between group t – tests used. Unclear whether used on all 	Supplemented qualitative feedback. Significant results for higher grief on survey items relating to the 7 main identified themes except systemic issues as there was no corresponding question in the scales.

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
				<ul style="list-style-type: none"> Hogan Grief Reaction Checklist 		participants for each theme)	
Schulz, Boerner, Shear, Zhang, Gitlin, 2006	Predicting complicated grief indicators among dementia caregivers	217 bereaved in home bereaved caregivers (part of REACH study)	Prospective longitudinal study	<ul style="list-style-type: none"> Inventory of complicated grief 	<ul style="list-style-type: none"> Centre for Epidemiological Studies Depression Scale State trait subscale of Speilberger state trait personality inventory MMSE ADL/IASL questionnaire Revised memory and behaviour problem checklist 	<ul style="list-style-type: none"> Pearson chi-squared, Cochrane Armitage trend test, or Wilcoxon Mann Whitney test <p>Dependent on criteria</p> <ul style="list-style-type: none"> Logistic regression models 	<p>Pre-death Complicated grief predictors ($p < .05$):</p> <ol style="list-style-type: none"> 1. Positive caregiving experiences (<0.0001) 2. Higher levels of depression (0.002) 3. Perceived higher levels of caregiver burden (0.02) 4. Lower MMSE scores (0.01) 5. Control (0.02) <p>Post-death complicated grief predictors:</p> <ol style="list-style-type: none"> 1. High post-loss depression (0.0001) 2. Time since death (0.003) <p>Complicated grief increased for first 15 weeks but then half spontaneously recover 6-12 months following death</p>

Table 2: Overview of Quantitative Studies

Author	Purpose of study	Participants	Design	Grief Measures	Other measures	Analysis	Results
					<ul style="list-style-type: none"> Positive aspects of caregiving were recorded through self devised questionnaire 		

Review of Quality of Quantitative Studies

Nine quantitative studies were reviewed of which three used mixed method designs (Meuser & Marwit, 2001; Adams & Sanders, 2004; Sanders et al., 2008). Evaluation of the rigour, as shown in table 3 indicates that all papers selected participants reasonably appropriately, explained their procedure clearly and drew appropriate conclusions, with an awareness of their limitations. In relation to some of the other criteria, the picture was more mixed.

In terms of scales used, as can be seen from table 2, where stated Cronbach Alpha is satisfactory for all when given in the study, though these are not always reported. Cronbach Alpha indicates whether all the items in the scale are measuring the same thing, for example, complicated grief (internal consistency). When assessing clinical populations, higher alphas of .9 and above are preferred, however over .7 is considered satisfactory (Bland & Altman, 1997).

Drawing from the criteria used to devise the table, the author notes the lack of power recorded by the studies except one (Adams & Sanders, 2004). Recording power in statistics is important as it reduces the likelihood of rejecting a hypothesis when there is an effect present (Type II error). To increase the power of a study, there are several considerations; sample size, number of variables, expected effect size and type of test (parametric are more powerful). The larger the sample and/or effect, the more likely a type II error has not occurred. Large participant numbers reduce the variability of the sample as they are more likely to be normally distributed (Gravetter & Wallnau, 1996). All studies had over 30 participants in their samples and for most this seems satisfactory for the type of analysis conducted. However Owen, Goode and Haley (2001) report statistical differences between African Americans and White caregivers, although the African American sample was small (16 participants).

Parametric tests are more powerful for yielding significant results, however, they require 3 assumptions to be met (normal distribution, at least interval data and if groups compared, equal distribution). Four out of the 9 studies used parametric tests (Meuser & Marwit, 2001; Owen, Goode & Haley, 2001; Ott, Sanders & Kelber, 2007; Sanders et al., 2008), without stating that assumptions for testing had been met.

Table 3: Quantitative Quality Criteria

Paper	Sampling		Ethical issues	Procedure	Measures	Analysis				Discussion			Star rating
	Selection	Sampling clearly defined	Awareness of ethical issues and consent	Procedure clearly explained	Appropriate measures of grief and comparison	Appropriate statistics	power	Confounds	Reporting statistics	Awareness of limitations	Appropriate conclusion	Generalisability	
Adams and Sanders, 2004*	1	2	0	1	2	2	2 (.98)	2	1	2	2	2	2 (20)
Boerner, Horowitz and Schulz, 2004	2	2	0	2	2	2	2	2	2	1	2	1	2 (20)
Holley and Mast, 2009	1	2	1	2	2	2	2	2	2	2	2	1	2 (21)
Meuser and Marwit 2001*	2	2	1	2	1	2	2	0	2	1	2	1	1 (18)
Ott, Sanders and Kelber, 2007*	2	2	0	2	2	2	2	2	2	2	2	2	2 (22)
Owen, Goode and Haley, 2001	1	2	1	2	1	1	1	2	1	1	1	1	1 (15)

Table 3: Quantitative Quality Criteria

Paper	Sampling		Ethical issues	Procedure	Measures	Analysis				Discussion			Star rating
	Selection	Sampling clearly defined	Awareness of ethical issues and consent	Procedure clearly explained	Appropriate measures of grief and comparison	Appropriate statistics	power	Confounds	Reporting statistics	Awareness of limitations	Appropriate conclusion	Generalisability	
Sanders and Adams 2005	2	2	2	2	2	2	2	2	2	2	2	2	24 (2)
Sanders, Ott, Kelber and Noonan, 2008*	2	2	0	2	2	1	1	1	2	2	2	1	1 (18)
Schulz, Boerner, Shear, Zhang & Gitlin, 2006	2	2	1	2	1	2	2	2	2	1	2	2	2 (21)

However, due to the robustness of parametric testing and the large sample sizes obtained, it is suggested that the results, which did not indicate assumptions had been met, will be acceptable even if the assumptions have been violated (Gravetter & Wallnau, 1996).

A number of the papers included no explicit consideration of ethical issues.

In addition to the generic quality indicators included in table 3, Sanders & Corley (2003) highlight two further, inter-linked areas of concern for quantitative literature exploring grief responses in dementia caregiving: 1) an overreliance on non-grief related measures which do not include all the domains of grief and 2) an inconsistent operational definition for grief. These are considered below.

Providing a consistent operational definition of grief in this field is difficult as grieving in dementia has many facets including: anticipatory, chronic and complicated grief, as well as different losses such as ambiguous, personal and interpersonal losses. Thus the definition may need to vary dependent upon the focus of the study.

In relation to the use of measures, all studies used at least one specific grief measure (none were excluded for lack of grief measure). Five studies used the Marwit and Meuser Caregiver grief inventory (MM-CGI) or its short form (MM-CGI-SF) which goes some way towards providing an operational definition of grief in dementia. Marwit and Meuser's instrument is designed to assess grief in caregivers of people with dementia across the illness trajectory and captures the different trajectories by relationship type (adult children and spouse). In a two stage process (Meuser & Marwit, 2001; Marwit & Meuser, 2002) they produced an overall caregiver grief inventory with 3 subscales: personal sacrifice burden, heartfelt sadness and longing, and worry and felt isolation. Each subscale was hypothesised to reflect the multi-faceted nature of grief in dementia caregiving. The total scale has an internal consistency reliability of .96 (Cronbach's alpha) with high content validity as items are rooted to caregiver statements from a previous focus group. Each subscale correlated highly with the total score and had high internal consistency (PSB .93; HSAL .90; WAFI .91). Modest correlations were found for comparison with depression scales and wellbeing scales, demonstrating good discriminant validity. The scale has convergent validity demonstrated by correlation with the Anticipatory Grief Scale (Pearson r_s .67-.80, Meuser & Marwit, 2001 as cited in Holley & Mast, 2009). Studies have also used the short form (Marwit & Meuser,

2005). Sanders, Ott, Kelber & Noonan (2008) reported the MM-CGI-SF had strong concurrent validity with the original study as the overall scale and subscales had good internal consistency (PSB = .83, HSAL = .84, WAFI = .78). Whilst, Ott, Sanders and Kelber (2007) used the scale as their definition of grief. The scale is provided in the overview of quantitative studies but the paper is not reviewed as critiquing scales is outside of the remit of this review.

The Anticipatory Grief Scale (AGS) was also used in four of the studies reviewed. This was developed by Theut, Jordan, Ross & Deutsch (1991, as cited in Marwit & Meuser, 2002). Based on 27 female spouse caregivers of dementia patients, Theut et al., (1991) developed a scale of 27 items which shows good internal consistency (.84) and good consistency with Meuser and Marwit's (2001) scale (.84). However Marwit and Meuser (2002) criticised the AGS as they state it was not empirically derived and was only validated against the Hopkins Symptoms Checklist (p.759).

Therefore, when comparing construction of the scales, Marwit and Meuser's two-process, caregiver data-based items and factor analysis, suggest more weight should be placed on the outcomes of studies which have used the MM-CGI or its short-form than the AGS.

In addition to these two scales, which operationalise grief in dementia, Meuser and Marwit (2001) devised the Many Faces of Grief questionnaire, based on grief literature in 5 domains (emotions, cognitions, physical, spirituality, and social). This scale is reported as having internal consistency of 0.93, however very little further information is provided about it.

Several of the studies reviewed were measuring post bereavement adaptation and used specific bereavement scales appropriate to this context.

Owen, Goode and Haley (2001) explored ethnic differences between White and African American families using a self devised bereavement questionnaire based on the Texas Inventory of Grief (TIG) and items about life sustaining treatment decisions, although no reliability or validity checks are offered. The Texas Inventory of Grief was devised as a brief scale to operationalise abnormal grief. Fifty-seven participants who had experienced a bereavement within the family were included. Only 13 participants had experienced a recent death (within 2 years of the study). Modest internal consistency (.69) and good split half reliability were found (.81) (Faschingbauer, Devaul & Zisook, 1977).

The Texas Revised Inventory of Grief (TRIG) measures separation distress and was used by Boerner, Schulz and Horowitz (2004). This is a common measure used in bereavement studies and is made of 2 parts. Cronbach's Alpha is satisfactory with .77-.87 for part 1 and .69-.89 for part 2. However, questions have been raised about the ability for the scale to distinguish grief from depression as there is considerable overlap in the scale (Burnett, Midleton, Raphael, & Martinek, 1997 as cited in Van Heck & De Ridder, 2008). Boerner et al., (DATE) were considering depression in post death adaptation however this is not covered within this review.

Schulz, Boerner, Shear, Zhang & Gitlin (2006) give an operational definition of complicated grief for their study and used the standardised Inventory of Complicated Grief (ICG; Prigerson et al., 1995). This scale was developed specifically to measure complicated grief reactions and was based on 97 widowed elders. (Depression has been extracted from the scale). The internal consistency of the 19- item ICG was high (Cronbach's alpha = 0.94) and test-retest reliability was 0.80. A score of greater than 25 is indicative of a complicated grief reaction. However, the authors also used a self devised scale to measure positive aspects of caregiving however no quality indicators are provided.

In summary, the quantitative studies reviewed define grief well though use measures that are variable in quality, with the MM-CGI being the best developed for assessment of grief in dementia caregivers. The systematic appraisal indicates that all can be judged as at least medium quality with Holley and Mast (2009); Ott et al, (2007); Schulz et al, (2006), and Sanders and Adams, (2005) in particular meeting most of the quality standards. Owen, Goode and Haley's (2001) study has several methodological flaws and their findings should be interpreted with caution.

Review of Quality of Qualitative Studies

Eleven qualitative studies were reviewed, including the three studies with a mixed method design, which were also reviewed in the quantitative section above (Adams & Sanders, 2004; Meuser & Marwit, 2001; Sanders, Ott, Kelber, & Noonan, 2008). Frank (2007) states that their study is a mixed method design however, no quantitative analysis has been undertaken and therefore the author can only comment on its qualitative methodology

(Bazeley, 2009). Table 4 gives an overview of the quality of each study which has been rated against the CASP (2009) criteria.

Evaluation of the rigour of the qualitative papers, as seen in table 4, indicates that all papers appropriately chose a qualitative methodology and gave a clear statement of their aims. All papers gave at least satisfactory reference to the existing literature. Attention to limitations of method was mixed: Papers either explored this in detail or did not report it. Data analysis was rigorous enough to score at least satisfactory on all papers. Ethical issues were slightly more considered in qualitative papers but not always addressed. Marwit and Meuser studies did not provide supporting quotes for their conclusions and it was very unclear in Silverberg, (2007) study who had provided the quotations. All of the research studies were relevant to the topic and most provided enough detail to suggest appropriate transferability of results within the limitations given, although less emphasis should be placed on Adams and Sanders (2004) and Frank (2007) due to their overall low scores and their lack of consideration of significant methodological concerns. Due to the quality criteria used for this particular review, Silverberg's findings are not commented on.

Highlighting specific flaws in the studies, the author notes the variation in data collection. Six of the studies conducted interviews with caregivers, whilst four involved analysis of written answers to open ended questions at the end of postal surveys. Three of these four studies were conducted by Sanders and colleagues (Sanders & Corley, 2003; Sanders, Morano & Corley 2003; Adams & Sanders, 2004) and the fourth was by Frank (2007). Although postal surveys may produce more honest answers and written responses are less influenced by researcher presence (Coolican, 1999), participants are unable to elaborate or clarify their responses. Therefore the extent of exploration of the area under question is somewhat limited.

Furthermore, Sanders and colleagues state that caregivers' responses to these questions were analysed using Strauss and Corbin (1990) or Padgett's (1998) methods; however no specific method was indicated reducing the ease of replication of these studies. Similarly, although Frank employed a very large sample and used a computer programme (N-Vivo) for analysis, no specific method or details on written responses were given.

Journal article	Adams and Sanders 2004*	Blieszner, Roberto, Wilcox, Barham and Winston 2007	Dupuis, 2002
Was there a clear statement of the aims of the research	2	2	2
Is a qualitative methodology appropriate	2	2	2
Links to theory/ reference to the literature	1	2	2
Was the sampling strategy appropriate to address the aims	1	1	2
Was the choices for selection of participants theoretically justified	2	2	1
Were limitations of method considered and explored?	0	2	2
Was the data collected in a way that addresses the research issue	0	2	2
Was the data analysis sufficiently rigorous	0	2	2
Ethical considerations and potential biases	0	1	1
Clear statement of findings	0	2	1
Links between data presented and own findings e.g. quotes	1	2	2
Were measures taken to test the validity of the analysis?	0	2	1
Are the findings transferable to a wider population	1	2	1
How relevant is the research	2	2	2
Star rating	1 (12)	2 (26)	2 (23)

Table 4: Qualitative Quality Criteria

Journal article	Frank 2007	Meuser and Marwit 2001	Robinson, Clare and Evans 2005	Sanders, Butcher, Swails and Power, 2009
Was there a clear statement of the aims of the research	2	2	2	2
Is a qualitative methodology appropriate	2	2	2	2
Links to theory/ reference to the literature	1	2	2	2
Was the sampling strategy appropriate to address the aims	1	2	1	2
Was the choices for selection of participants theoretically justified	1	2	2	2
Were limitations of method considered and explored?	0	1	2	2
Was the data collected in a way that addresses the research issue	1	2	2	2
Was the data analysis sufficiently rigorous	1	2	2	2
Ethical considerations and potential biases	0	0	2	2
Clear statement of findings	2	1	2	2
Links between data presented and own findings e.g. quotes	1	0	2	2
Were measures taken to test the validity of the analysis?	0	0	2	2
Are the findings transferable to a wider population	1	1	2	2
How relevant is the research	1	2	2	2
Star rating	1 (14)	1 (19)	2 (27)	2 (28)

Table 4: Qualitative Quality Criteria

Table 4: Qualitative Quality Criteria

Journal article	Sanders and Corley 2003	Sanders, Morano and Corley (2002)	Sanders, Ott, Kelber and Noonan, 2008*	Silverberg 2007
Was there a clear statement of the aims of the research	2	2	2	1
Is a qualitative methodology appropriate	2	2	2	2
Links to theory/ reference to the literature	2	2	2	2
Was the sampling strategy appropriate to address the aims	1	1	2	0
Was the choices for selection of participants theoretically justified	2	1	2	0
Were limitations of method considered and explored?	0	0	2	0
Was the data collected in a way that addresses the research issue	1	1	2	1
Was the data analysis sufficiently rigorous	2	1	2	1
Ethical considerations and potential biases	0	1	1	0
Clear statement of findings	2	2	2	0
Links between data presented and own findings e.g. quotes	2	2	2	0
Were measures taken to test the validity of the analysis?	2	2	2	1
Are the findings transferable to a wider population	1	1	2	1
How relevant is the research	2	2	2	1
Star rating	2 (21)	1 (20)	2 (27)	0 (10)

Thus these findings should only be considered in conjunction with other more in-depth qualitative research as they give only a superficial understanding of the topic under exploration.

In conclusion, the quality of the qualitative studies is of a medium standard. Only Silverberg (2007) is of poor quality and therefore has been removed from the findings. Inclusion in the table is to illustrate the quality of papers reviewed. Particularly good papers are Blieszner et al., (2007); Dupuis (2007); Robinson et al (2005), Sanders et al., (2009), and Sanders et al., (2008).

A Note on Mixed Methods Designs

Meuser and Marwit (2001) quote Neimeyer and Hogan (2001)'s views on combining qualitative and quantitative approaches. They stated that this produces a "methodological pluralism which respects both numbers and narratives and the distinctive forms of understanding that each can promote" (p.113). Thus whilst there may be limitations in those studies with mixed methods reviewed here, this particular strength is also noted.

Findings of Studies

The sections below each relate to research pertinent to different stages of dementia (mild cognitive impairment, mild, middle and late dementia, end of life and all stages) and finally a separate section on those who report that they are not grieving. Findings relevant to each area are presented and discussed below, and the weight placed on the findings should be based on the comments above.

Mild Cognitive Impairment (MCI)

Only Blieszner, Roberto, Wilcox, Barham and Winston (2007) have explored loss and MCI. They explored ambiguous loss in spouses of people who had MCI. Mild cognitive impairment is considered the transition between normal aging and dementia and is associated with memory loss and diminished cognitive processes which are assumed not to affect overall daily functioning. The authors found that a sense of uncertainty due to the nature of changes caused by MCI occurred at the early stages. They concluded that the loss and grief described by partners of individuals with MCI appeared to follow a similar trajectory to that described by caregivers of people with dementia. Spouses struggled to understand the changes in their

partner and this was further exacerbated when their partner appeared unimpaired as their long-term or routine memory compensated for cognitive deficits. As a result of this, spouses were unsure whether there was a problem and therefore tried to continue as normal. This ambiguity increased the level of distress which was experienced.

Spouses reported significant changes in their lives, including loss of personal freedom and distress brought on by the changes in the person with MCI. Coping decreased in those who described poor relationships prior to the MCI. Couples reported coping by taking “one day at a time”. The authors suggested that difficulty dealing with changes occurring in the earlier phases may increase a potential caregiver’s vulnerability if the disease progresses. The participants’ descriptions suggest that spouses do not see themselves as caregivers however due to the significant changes experienced and the number of roles that they have taken on, their relationship with their spouse has, all the same, changed. Blieszner et al., (2007) suggest an appropriate term to describe their position may be “care partner”.

Although only one study has explored MCI, it suggests that MCI has a lot of parallels with dementia and that loss and grief should be considered as soon as any cognitive changes are identified.

Early Stages (Mild Dementia)

Grief during the early stages of dementia appears to oscillate between denial / emphasis on relatives’ and caregivers strengths *and* feelings of sadness about what has already been lost and what is going to be lost in the future (Adams & Sanders, 2004; Meuser & Marwit, 2001). Robinson, Clare & Evans, (2005) who explored couples with a partner recently diagnosed with dementia suggest this may occur in a cyclical process over a long period of time as they move towards acceptance that dementia is permanent.

Adams and Sanders (2004) and Meuser and Marwit (2001) explored among other things, relationship differences in caregiving for early dementia. Although Adams and Sanders (2004) did not find differences between spouses and adult children, Marwit & Meuser’s stronger evidence suggests that spouses appear to be more in touch with their feelings and the illness progression, whilst adult children are more likely to be avoidant and stress their parent’s strengths. Grief is not acknowledged but is suggested in statements of what the parent “was” like. Adult children focused more on personal losses whilst spouses

focused around the lost relationship. Diagnosis is suggested as a “grief peak” for spouses (Meuser & Marwit, 2001).

Schulz et al., (2006) found some caregivers may be in denial at this stage and are still caregiving at home even though it is clear that they are not coping. They stated that these caregivers may have a very strong attachment bond and may be at a higher risk of developing a complicated grief reaction.

However, Silverberg (2007) quotes Marwit, Meuser and Sanders (2004) who argue that it is important not to see denial just as an early grief response and that it may also be due to family dynamics. She also considers their position that with such a long progression, denial should not always be considered a negative response and may be adaptive for caregivers in the beginning as a way of coping with the demands placed on them.

Continued ambiguity around whether the person with dementia still exists as themselves is also observed within the mild stages and again, reported to intensify the grief reaction. Loss of communication is hard for relatives of a person with mild stage dementia to adapt to (Adams & Sanders, 2004).

Although spouses spoke of a sense of togetherness and were anticipating changes, they also said that they would prefer to die first rather than watch the decline of their loved one (Meuser & Marwit, 2001).

In summary, adult children do not appear ready to consider the long term implications of their parent’s dementia. They may be in denial and tend to focus on their parent’s strengths. Spouses are more in touch with their feelings and are concerned with the changes between them and their partner. Ambiguity continues to increase the level of distress caregivers’ experience.

Middle Stages (Moderate Dementia)

Studies suggest that as a person moves from the mild into the moderate stages of dementia, feelings of grief and loss in caregivers intensify (Adams & Sanders, 2004; Sanders, Ott, Kelber, & Noonan, 2008; Meuser & Marwit, 2001; Ott, Sanders & Kelber, 2007).

Sanders et al., (2008) identified 7 main themes in accounts of caregivers of people in the moderate and severe stages of dementia who were experiencing high grief reactions. These were: yearning for the past, regret and guilt, isolation, restricted freedom, life stressors, systemic issues and coping strategies. Yearning was found to be important in this phase, as caregivers spoke of longing for the past and being caught in a never ending process of grief because they are stuck in a “living death” (Sanders et al., 2008). Those whose care recipients were still at home reported more isolation as the care demands increased, with this being especially so for those who had previously relied on their relative for support.

Adams & Sanders (2004) found personal losses are focused upon during this stage, especially a loss of freedom and time, with caregivers reporting that their thoughts as well as their actions were taken up with caregiving. This was regardless of the care recipient’s location e.g. home or care home. Some caregivers in the middle stages reported that they wished that their relative was either “all there or all gone” (Adams & Sanders, 2004).

Some authors suggest adult children and spouses follow different trajectories (Sanders, Ott, Kelber & Noonan, 2008; Meuser & Marwit, 2001). Adult children are reported as going through a gamut of emotions: guilt (Sanders et al, 2008; Meuser & Marwit, 2001), regret (Sanders et al, 2008) and anger (Meuser & Marwit, 2001), with this being indicative of grief. The adult children were found to be more active in making care decisions and had begun to recognise their losses as their relationship with their parent changed. Marwit and Meuser (2001) note that adult children cannot think about their future and have fears of the likelihood of developing dementia themselves. They suggest that grief is highest for adult children in this phase.

Yearning, isolation and restricted freedom were reported more by spouses than by adult children within Sanders et al., (2008) study. Spouses work at keeping the connection with their partner alive and recognise that they are grieving the number of losses that they have experienced (Sanders et al., 2008), yet they may also be redefining their relationships and move towards thinking of their spouse as a “beloved child” (Meuser & Marwit, 2001). Sanders et al., (2008) also found spouses are more likely to have stronger grief responses if there are multiple life events occurring and their own health is poor and/or if they have placed their loved one into a care home (Meuser & Marwit, 2001).

So during the middle phases, it seems as if the adult-children who denied loss and hung on to the idea of their parent as strong earlier, now go through realisation and grieving, which has quite an element of guilt and regret whereas the spouses experience less complex grief perhaps because they started to grieve more openly earlier.

Late Stages (Severe Dementia)

Adams and Sanders (2004) and Ott, Sanders and Kelber (2007) suggest that grief of relatives within the late stages of dementia moves towards a greater focus on interpersonal losses and relationship changes, and in this way it is closer to post-death grief. However, although Meuser and Marwit (2001) observed this for adult children, they noted that when spouses' partners move into a care home, spouse's grief includes or is superseded by thoughts of themselves as they start to move towards individuality but are still bound by their duties as a married couple. Guilt and regret are felt keenly by spouses at this time. Higher grief and depression scores were recorded by Adams and Sanders (2004) indicating levels of grief comparable to post-death grief, and scores on the MM-CGI suggested they were "at risk" of problematic grief reactions.

Schulz, Boerner, Shear, Zhang and Gitlin (2006) found that higher levels of cognitive impairment were linked with greater reported levels of grief post-death. One suggestion is that this is due to caregivers' depleted resources. Emotions and responsibility are more intense (Meuser & Marwit, 2001) and the sense of confusion around whether the person with dementia is themselves or should be viewed as already gone was also observed in the later phases and caused distress for caregivers (Adams & Sanders, 2004).

Marwit & Meuser (2001) observed changes in quality of grief at this stage for both spouse and adult children with grieving seemingly provoked for different reasons than at earlier stages. Adult children are depleted by the previous losses experienced and have started to accept an idea that their parent is no longer their parent and refer to a "true grief of the soul" (p.665). This leads to feelings of sadness which replace the earlier feelings of anger and jealousy. Marwit and Meuser also observed some positives at this stage for adult-children who suggest a changed outlook or show more feelings of empathy towards their ill parent as they indicate an understanding of what their parent must be going through. Spouses however are more stuck between moving forward alone and being aware of the end of their relationship

with their partner, who is still alive but no longer the person that they married. Also, unlike adult children, spouses recognise that they have more intense grief to come and are not seeking their partner to die as a way to resolve the situation (Meuser & Marwit, 2001).

Therefore, the late stages of dementia suggest a particularly difficult time for adult children and spouses for different reasons. Adult children's grief now focuses on the losses and missed opportunities with their parent and speak of the "long goodbye to their parent" (p.665). Spouses, however, are caught in a limbo between their role and their move towards a life alone which can be frightening. They are aware of more grief to come and at this point, feelings of anger and frustration are common (Meuser & Marwit, 2001).

Care home Facilities

Transition to a care facility has been found to trigger intense grief reactions, especially in spouses who are being separated from their partner (Sanders, Ott, Kelber, & Noonan, 2008; Ott, Sanders & Kelber, 2007; Dupuis, 2002; Marwit & Meuser, 2001). Focus of loss appears to move towards the self at this point for spouses (Meuser & Marwit, 2001; Ott, Sanders & Kelber, 2007).

Dupuis (2002) explored ambiguous loss in detail in relatives of care-recipients going into a care home, proposing a model of ambiguous loss, based on Boss' (1999) theory, to understand the experience. Her research is conducted in a Canadian setting where individuals with dementia may move to live in a care home with mild symptoms. Since this would not usually occur in the UK these findings should be taken with caution in the UK context. Dupuis suggested that adult children go through a number of stages associated with ambiguous loss which appear to map onto a care recipient's journey in dementia within a care home: anticipatory (mild), progressive (moderate) and acknowledged loss (severe). Dupuis has put forward the theory that ambiguous loss is not stable but is lived through in that the relative initially experiences fears for the future and an awareness of the difficulty that lies ahead. As the illness progresses, these experiences start to occur and the person then moves into "progressive loss". Ambiguity is hardest here as the person tries to make sense of the physical presence of the person whilst the essence of the person continues to fluctuate. Finally the adult child enters "acknowledged loss", where they recognise that their parent is no longer "present". Dupuis suggests acknowledged loss can take two forms: accepting or avoiding.

Those who cope by avoiding express more distress about their situation and appear “stuck”. Of note, family members may experience these phases at different times, which can cause further loss and grief for the family. Frank (2007) offers support to Dupuis’ (2002) model of ambiguous loss by suggesting spouses appear to follow a similar trajectory.

End of life

End of life issues and death have not been overly explored within dementia. However this is important as not only may the caregiver have to consider care home placement, the caregiver may also have to respond to requests from staff about end of life care. Such decisions have been found to affect how relatives later respond to the death of their loved one (Owen, Goode, & Haley, 2001). An area which has received practically no attention is differences in culture and end of life care. Owen, Goode and Haley (2001) explored differences between African American and ‘White’ caregivers’ attitudes towards end of life treatment and death. They found that African Americans described that they are significantly less likely to withhold life-sustaining treatments. The authors suggest this could be due to spiritual/cultural beliefs or lower rates of access to health care. However, with only 16 African American participants, a self devised questionnaire and no supporting studies, this area requires further investigation.

Sanders, Butcher, Swails and Power (2009) addressed how caregivers perceived the end stages of dementia within a hospice environment. They found that caregivers fell into 4 main ways of approaching the end of caregiving: disengaged, questioning; all consumed and reconciled, which they remained in throughout the study. Issues of unaddressed loss and grief were most expressed in All Consumed caregivers. Grief focussed around lack of connection/interaction, marking time and pining “for what could have been”. All consumed caregivers were also more worried about hospice involvement ceasing before death and were more likely to have ongoing other life events. Of note, the only 2 home caregivers both fell into this category. Questioning caregivers were hypothesised as possibly being in a state of denial as they would question the appropriateness of having hospice care and had the second highest level of distress reported. Disengaged caregivers expressed feelings of anger and poor pre-diagnosis relationships although they reported that they had ‘closure’. Disengaged caregivers felt burdened by the caregiver and were “longing to be free” (p.539). The authors suggest post death grief reactions may occur for disengaged caregivers due to lack of earlier

resolution of the issues such as conflict. Reconciled caregivers have accepted and are prepared for the death of their relative. All were older and had previously experienced a number of deaths and they remained active in the person's care.

Death and Bereavement

Literature has been mixed about whether the death of a care recipient following prolonged caregiving leads to increased depression, grief and distress because the caregiver has depleted resources or improvement as the care recipient is no longer suffering and caregiver burden has been lifted. Bodnar and Kiecolt-Glaser (1994 as cited in Owen, Goode & Haley, 2001) found in their longitudinal study that bereaved caregivers showed similar levels of depression as those who are still caregiving, suggesting that bereavement neither resolves nor increases a caregiver's distress. However, some state that the majority of studies suggest an improvement in caregiver wellbeing (Boerner, Schulz & Horowitz, 2004; Owen, Goode & Haley, 2001).

Meuser and Marwit (2001) found that adult children reported relief and reduction in their grief immediately after the death, although it subsequently increased as they tried to make sense of this loss. However, they also found that adult children reported personal growth as well as grief as they adapted to bereavement, such as becoming more compassionate and understanding. Spouses reported that their grief was ongoing throughout caregiving and after death.

Ethnic differences have also been explored (Owen, Goode & Haley, 2001). African Americans responded in an author devised questionnaire that they were less likely to prepare for a death, for example, make funeral arrangements, or consider the death prior to its occurrence and reported a greater sense of loss on the death of their loved one. The authors suggest this may be because more African Americans died at home and therefore caregivers had more contact and continuing emotional investment, in the days leading up to their death. Alternatively, they suggest White caregivers may be more aware of symptomatology as it is perceived that they are more familiar with healthcare systems and therefore are relieved that the suffering of their loved one has ended. However, as indicated above, methodological flaws suggest this finding should be taken with caution.

Although the majority of caregivers will successfully grieve without intervention, some caregivers will go on to have a complicated grief reaction. In a study by Schulz et al., (2006), they found 43 caregivers (19.8%) met the criteria for a complicated grief reaction. Studies exploring complicated grief reactions have found positive caregiving experiences, higher levels of depression, perceived higher levels of caregiver burden, lower MMSE scores, marriage and poorer caregiver health are pre-death predictors whilst higher depression scores post-loss and greater time since death are post-death predictors of complicated grief (Schulz, Boerner, Shear, Zhang & Gitlin, 2006; Boerner, Schulz, & Horowitz, 2004). Boerner et al., (2004) found positive caregiving benefit was linked with higher levels of grief when other known factors had been accounted for. The authors suggest this may be because those spouses who derive more meaning from the role also had a strong attachment or a high level of dependency on the care recipient (Schulz et al., 2006).

Cognitive impairment was also an independent predictor with caregivers who look after a more cognitive impaired relative reporting greater grief on their death (Schulz et al., 2006). Their findings suggest that complicated grief increases during the first 15 weeks post-death but then decreases in the subsequent 6 to 12 months and 50% of those suffering a complicated grief reaction recovered without intervention. However they recommend that if present, targeted interventions are needed.

All stages

Several studies have looked at grief across the illness trajectory rather than focusing only on one stage of dementia or make inferences about grief responses across the stages (Holley & Mast, 2009; Sanders, Ott, Kelber & Noonan, 2008; Ott, Sanders, & Kelber, 2007; Frank, 2007; Adams & Sanders, 2004; Sanders & Corley, 2003; Meuser & Marwit, 2001). Grief in dementia has been reported as more chronic than in other illnesses due to the average duration of 8 years of life post-diagnosis alongside the cognitive and physical decline of the care recipient (Ott, Sanders & Kelber, 2007), leading to a label of “chronic grief” (Sanders & Corley, 2003). Caregiver grief responses as well as adult children and spousal differences and similarities have been researched. Dementia caregivers report ambiguity, multiple losses and the chronic nature of grief as contributing to their feelings of desperation and loss of control (Sanders & Corley, 2003). Role reversal has been highlighted as being particularly salient as this demonstrated that the relationship would never return to “normal” (Sanders & Corley,

2003), and stage of disease appears to have an impact on caregiver grief and depression (Adams & Sanders, 2004; Meuser & Marwit, 2001).

Meuser and Marwit (2001) suggest that the trajectories have different emphases for adult children and spouses, however the level of grief experienced appears to be similar (Ott, Sanders & Kelber, 2007; Meuser & Marwit, 2001). Adult children's dementia trajectory is suggested as being curvilinear with a peak in the middle stages following initial denial and later acceptance. Their grief initially is more anger based and centred on self, with jealousy of others, negativity, loss of interest in usual activities and questioning of the meaning of life. As their parent declines, they become more reflective, experiencing sadness focused on the loss of the parent and relationship. Ott, Sanders & Kelber, (2007), found more adult children than spouses are likely to report health related changes since their parent became ill and they may use substances, vent, reframe and use humour to cope with their grief. However, Ott, Sanders and Kelber (2007) also explored personal growth following caregiving in dementia. Growth was categorised as becoming "more caring and connected to others, evaluating what is really meaningful in life and reassigning priorities... following difficult life events" (p.799 Hogan & Schmidt as cited in Ott, Sanders & Kelber, 2007). More adult children appeared to experience more personal growth than spouses and personal growth was related to social support and coping by reframing or religion. Growth was also noted for adult children in Meuser and Marwit (2001) study.

Spouses appear to follow a more linear trajectory with ongoing grief throughout the process, focused around loss of sexual intimacy, loneliness and ambiguity (Sanders & Corley, 2003; Meuser & Marwit, 2001). As loss of sexual intimacy occurs, grief is reported to intensify as well as feelings of anger, isolation and rejection (Sanders & Corley, 2003). Spouses' grief as measured on grief scales also becomes intensified when they place their partner into a care home (Ott, Sanders & Kelber, 2007; Meuser & Marwit, 2001). Emotionally, spouses change from feelings of sadness to anger and frustration. Loss of couplehood is replaced by thoughts of self in the final stage.

Anticipatory grieving, ambiguity and contributors to grieving have also been explored (Holley & Mast, 2009; Frank, 2007; Sanders & Corley, 2003). The sense of being unable to assimilate the fact that the person is physically present but psychologically absent was reported as affecting caregivers' feelings towards the person, their ability to cope with the

changes and how the illness would continue to impact on them and potentially could become a barrier to caregiving (Frank, 2007; Sanders & Corley, 2003). A number of studies have found that caregiver burden appears to be linked with higher levels of anticipatory grieving (Holley & Mast, 2009; Frank, 2007; Marwit & Meuser, 2002). Holley and Mast (2009) build on previous work (Marwit & Meuser, 2002; 2005; Walker & Pomeroy, 1997) and suggest the explanatory power of caregiver burden models can be improved upon by including grief and loss. For some, the length and unpredictable nature of dementia had lead to thoughts of suicide and taking the life of their loved one (Sanders & Corley, 2003).

Sanders, Morano and Corley (2002) looked specifically at males' experiences of grief across the dementia journey. The authors suggest that men grieve differently to women and often refuse help, try to hide their emotions and do not assess support. Men often rely on their spouse for support and when she is not there, they do not have the skills through lack of practice or inclination to try. Sixty eight percent of male caregivers reported that they were grieving for their loved one even though she was still alive. Grieving fell into two main themes: crisis through watching the deterioration (experienced by 16 of their sample), and losses encountered as they provided care (experienced by 32). Male caregivers talked most about a loss of communication, loss of intimacy, activities and relationship. Personal growth was identified in those male caregivers who could see that they were changing and growing in light of their role. Losses were identified as both primary and secondary, including loss of communication and the loss of dreams and the future.

Not Grieving?

In three studies, some caregivers reported that they were not grieving (Adams & Sanders, 2004; Sanders & Corley, 2003; Sanders, Morano & Corley, 2003). Adams and Sanders (2004) found some caregivers who reported that they were not grieving, although the number decreased across the stages in their study. Caregivers in the early stages focussed on the things that their relatives could do whilst caregivers in later stages made reference to having already grieved but moved on and accepted their 'new' relative. Sanders and Corley (2003) suggest that it appears to be difficult for caregivers to identify their own grief since many reported that they were not grieving (32%). Some of those who report that they are not grieving the loss of their loved one cite relief at what their loved one can do and the time they have left together. Others reported that they were not grieving because of their strong faith.

Finally, some who had conflictual relationships were less likely to report that they are grieving, although personal losses and anger were prevalent in their accounts. It is possible that some of these caregivers were in denial at the time that they were interviewed. As noted above, this may be adaptive for the caregiver.

Sanders, Morano and Corley (2003) also found some male caregivers answered that they were not grieving for a loved one whilst they were still alive (23/71 caregivers). These caregivers stated that they "... [were] not grieving, but I do feel pain and loss" (p.12). Lack of grief came in 2 forms: emotional dissociation and "life could be worse" (p.12). The authors suggest that these caregivers are experiencing losses and are grieving, however they are not able to acknowledge it for fear that it would impede caregiving, do not feel able to express it as the person is alive or are more concerned about the strengths their relative has.

Conclusions

Grieving prior to the physical death of the person with dementia is clearly indicated, right across the stages of dementia, with some differences being apparent between men and women, and between adult-child and spouse caregivers. Although discrepancies have been found, the literature suggests that grief responses appeared to be affected by severity of disease and transitions (e.g. diagnosis and care home placement), relationship status, and, possibly, cultural factors.

Grieving of relatives in response to dementia is lengthy with multiple losses and ambiguity, which make it difficult for caregivers to understand their grief. The grief and loss which caregivers experience before death appear to be reflective of what is considered "true grief" rather than being anticipatory grieving for their relative's future death.

The above literature review supports the suggestion that grief can usefully be added to current stress-burden models of caregiving. Factors that contribute to burden (isolation, restricted difficulties) may also contribute to a sense of grief and loss, but there are also distinct aspects of grief (e.g. feelings of yearning, regret and guilt) which need to be added to stress-burden models to provide a clearer and fuller picture of caregivers' experiences during and after caregiving (Sanders, Ott, Kelber, & Noonan, 2008; Ott, Sanders, & Kelber, 2007).

In addition to the ongoing element of ‘true grief’, there is also some anticipatory grieving, and some suggestion that this may help adaptation to bereavement in the short term.

Grief as a barrier to caregiving, especially associated with the uncertainty around whether a person still exists for the caregiver, appears to be well established and adds weight to Boss’ ambiguous loss theory within dementia. Ambiguous loss/grief within dementia caregiving is inescapable, starts early in the process of dementia and continues throughout leading to grieving over a long period.

Unaddressed difficulties can lead to an increased risk of higher levels of depression, caregiver burden and complicated grief reactions. Sanders, Ott, Kelber and Noonan (2008) offer a profile of caregivers who are at risk from psychological and physical difficulties: yearning for the past, regret and guilt, isolation, restricted freedom, other life stressors and having difficulties with services. Although some caregivers may state that they are not grieving, it appears that aspects of loss are still apparent in their experience. Non-grievors indicated using a number of coping strategies (focus on the positive or on religion) which they suggested kept them from grieving or alternatively, grief may not have been expressed due to its disenfranchised nature. Therefore grief and loss should be considered even when the caregiver does not report it.

Limitations of study

Conducting literature reviews is an acquired skill, and the author is aware of her limitations compared to a more experienced researcher who may be more versed in identifying papers, critiquing them and summarising the findings (Aveyard, 2007). Many of the included papers highlighted the overlap between grief and depression and their papers reported on both areas, however, the author focussed on only the grief responses within the papers. The inclusion/exclusion criteria excluded a number of papers which may have proved fruitful to our understanding of loss and grief in caregiving for those who have dementia, for example, Sanders, Marwit and Meuser have written a number of papers reviewing their model of caregiver grief in dementia based on hypothetical cases and exploring interventions for caregivers who are grieving (Sanders, Marwit, Meuser & Harrington, 2007). Similarly, Noyes et al., offer a model of caregiving grief which incorporates both the stress-burden and grief literature however they undertook no independent study of this. A dissertation by Ross (2008)

detailing an assessment of anticipatory grief was also not included. Inclusion of such papers could have led to an extended focus on theoretical frameworks.

Therapeutic Implications: Interventions

Through reviewing the above literature, a number of suggestions can be made for potential interventions. Authors state the need to ensure interventions are ongoing throughout the process (Frank, 2007; Sanders et al., 2009) and are adapted to the needs of the relationship type (Frank, 2007; Meuser & Marwit, 2001) and/or stage of disease (Dupuis, 2002; Meuser & Marwit, 2001). Blieszner et al., (2007), Robinson et al., (2005) and Marwit and Meuser (2001) illustrate that interventions need to consider individuals from the moment that they present to services with memory changes as diagnosis has been recognised as a particularly difficult time for people with dementia and their caregivers. Due to the complexity of grief in dementia, the level of distress reported and the possibility that caregivers may feel the need to hide their grief, several authors have suggested the need for regular assessment of grief, including assessment of risk to self and the care recipient (Sanders, Ott, Kelber, & Noonan, 2008; Sanders et al., 2009; Sanders, Morano & Corley, 2003; Sanders & Corley, 2003). Interventions should address the isolation, lack of understanding about the illness, awareness of the illness, normalising the grief reaction, acknowledging losses, keeping the connection with the person with dementia and exploring the right time to say “goodbye” (Frank, 2007; Sanders et al., 2008; Holley & Mast, 2009). Specifically interventions should target anticipatory grieving (Holley & Mast, 2009; Boerner et al., 2007) and ambiguous loss (Blieszner et al., 2007; Sanders & Corley, 2003; Dupuis, 2002) prior to the loved one’s death as this may reduce the chances of a complicated grief reaction (Boerner et al., 2007). A number of intervention styles are suggested with psycho-educational groups or support being most frequently recommended (Holley & Mast, 2009; Sanders et al., 2009; Sanders et al., 2008; Blieszner et al., 2007; Frank, 2007; Boerner et al., 2004; Sanders & Corley, 2003; Sanders, Morano & Corley, 2003; Dupuis, 2002; Meuser & Marwit, 2001). Further interventions suggested include counselling and family counselling (Dupuis, 2002; Sanders & Corley, 2003; Blieszner et al., 2007; Sanders et al., 2009) and peer support (Holley & Mast, 2009; Sanders et al., 2008; Frank, 2007; Dupuis, 2002).

Implications for future work

Although research into grief and loss in dementia is growing, there is clearly more exploration which needs to be conducted. Most of the research is cross-sectional, has small data sets or looks at specific areas. Longitudinal studies, larger data sets, and assessing responses using grief sensitive dementia measures are suggested for future research to build a more comprehensive picture. Areas where little attention has been paid or differences have been found include the notion of care partners and ambiguous loss in MCI, gender, culture and grief, coping and personal growth. The effects of positive caregiving benefit have started to receive more attention and further work is needed to build upon this. Research into intervention, what tasks or rituals caregivers go through, and whether high grief as defined by the MM-CGI indicate a potential complicated grief reaction also needs further exploration. Clearly, the picture of grief and dementia is building but it currently remains an unfinished jigsaw puzzle.

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EMPIRICAL PAPER

**THE CONTINUED IMPACT OF YOUNG ONSET DEMENTIA ON DEPENDENT
CHILDREN AS THEY MAKE THE TRANSITION INTO ADULTHOOD –
A FOLLOW UP STUDY TO ALLEN, OYEBODE AND ALLEN (2009)**

By

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Abstract

The current study addresses the lack of longitudinal data by continuing Allen, Oyebode and Allen's (2009) study exploring perceptions of young people with a father with dementia. Seven young people agreed to be re-interviewed about their ongoing experiences. Utilising the Grounded Theory approach the researchers offer a model of young people's experiences of living with and being bereaved of a father with young onset dementia which is conceptualised as a 'journey'. Four processes were identified; Coping, Grieving, Questioning, and Growing through which the young people appear to move over the course of the illness trajectory and death. Moving between processes appeared to be influenced by the demands on the young person at the time, their father's stage in the illness and salient 'turning points'. Becoming 'stuck' within a process indicated that a young person may be at risk of complications such as questioning their own identity. However, the accounts suggest that despite the stress and distress of this period in their lives posttraumatic growth may eventually occur in the lives of these young people.

Keywords: children, grief, personal growth, stress-burden, young onset dementia

Introduction

Dementia is a syndrome caused by a range of illnesses, including Alzheimer's disease, vascular disease, frontal lobe dementia and Lewy Body disease, which results in progressive, irreversible brain damage and eventual death (Mathers & Leonardi, 2000). There have been developments within the UK Department of Health to increase awareness and understanding of dementia. Historically, misunderstanding has led to perceptions that dementia is a disease of 'old age' which has stopped younger people from accessing services when difficulties first arise (DoH, 2008). Although dementia is more common over the age of 65, there are a significant number of individuals who develop young onset dementia (under the age of 65 years old). The Alzheimer's Society Position Statement (2007) estimates that there are over 18, 000 younger people with dementia in the UK alone and there are now dedicated young onset dementia services (Harvey, Skelton-Robinson & Rossor, 2003).

There are a number of difficulties for individuals who develop young onset dementia. Often diagnosis can take up to several years with the person undergoing many investigations (Sharp & Cosgrove, 2006). Uncertainty, distress and frustration for the family are common (Mather, 2006). The needs of younger people with dementia and their families are different from those of people who develop dementia in later life (Beattie, Daker-White, Gilliard, & Means, 2002; Luscombe, Brodaty & Freeth, 1998). Often they are still providing for a family when they are diagnosed but due to the nature of the illness individuals typically have to give up employment. This can lead to financial strain and loss of independence for the family. Children are often still at home and reliant on their parents (Keady & Nolan, 1999). Luscombe et al., (1998) found 92% of carers in their study reported that children had been affected in some way by living with dementia.

However, very little is known about the impact on children. Since the mid 1990s there have been 6 published studies which have included children who have a parent with young onset dementia: Beach (1994), Robertson, (1996); Beach, (1997); Davies, Clovis, Ingram, Priddy and Tinklenberg (2000); Szinovacz (2003) and Allen, Oyebode and Allen (2009). Only Allen et al., (2009) have explicitly explored children's perceptions of having a parent with young onset dementia. Obtaining the views of young people directly is important however as parents may not appreciate their children's perspective. Szinovacz (2003) found

discrepancies between parent and adolescent accounts, with parents more likely to report positive effects of caregiving on children than their children perceived.

Two main theoretical underpinnings, attachment and resilience, appear to emerge from the studies as being relevant to understanding the impact on a young person's development when living with a relative with dementia.

Adolescent Development

Adolescence is a critical time period when children make the transition into independent young adults. The process involves physical maturation, cognitive development and social development. Adolescence is a time of self-exploration, during which the adolescent enters a process of discovering themselves and how they fit in the world. They gain greater autonomy and start to move away from their parents. Parents assist this transition by providing a secure attachment base and modelling (Carr, 2006).

Although the majority of adolescents go through the process without any long term difficulties, some may experience transient difficulties in adolescence, whilst others may be affected for longer (Steinberg & Sheffield Morris, 2001). Difficulties may arise for the adolescent when there is an incongruence between their specific needs and the opportunities for development (Eccles et al., as cited in Compas, Hindren, & Gerhardt, 1995).

Impact of Caregiving in Dementia on Adolescent Development

Research suggests adolescent development, especially of older adolescents, can be affected by the caregiving environment as although the well parent is usually the main caregiver, children are often involved in care tasks and their parents may not be available to them due to illness or being heavily involved in the caregiving. This can lead to a lack of emotional availability for the young person and opportunities to observe an appropriate role model. Heavy involvement with caring coupled with feeling abandoned by one or both of their parents may lead young people to experience difficulties in forming their own identity (Davis et al, 2000; Duncan & Reder, 2000; Compas, Hindren, & Gerhardt, 1995). By contrast to this position, Beach's (1997) study found that the caregiving situation appeared to facilitate

an adolescent's development as they grew in independence through taking on family responsibilities.

Impact of Stress Burden on Adolescent Development in Dementia Caregiving

During development, it is known that some factors place adolescents at risk of long term difficulties whilst others can protect against risk. Traumatic or stressful life events such as parental illness are considered potential risk factors (Compas, Hindren, Gerhardt, 1995).

Children in young onset dementia families were found to be bearing the stress of the parent caregiver and experienced a reversal of the parent-child role (Szinovacz, 2003). Role reversal identified in other situations has been associated with excessive burden on children which may lead to a sense of failure that they carry with them into adulthood, if they cannot tolerate it (Earley & Cushway, 2003). Educational, social and emotional well-being have also been found to be affected in young people assisting in care duties in other chronic illnesses (Alridge & Becker, 1999) and Bolas, Van Wersch, & Flynn, (2007) found that adolescents were at risk of ill health and were reluctant to disclose their distress.

Davies et al (2000) looked at children, coping and dementia and proposed that children appear to go through 4 stages of resolution before they are able to accept that their parent has dementia: awareness, explanation, attribution and integration. They stated that knowledge was critical for children to be able to accept their parent had dementia and the child must undertake several tasks for healthy adjustment, including allowing themselves to grieve, redefining their relationship with their parent with dementia and adapting to the altered family system.

Impact of Grief on Adolescent Development in Dementia Caregiving

Within the adult dementia literature, it is well established that due to the nature of dementia, the attachment to a relative is threatened before their death due to the psychological fading of the person. This can potentially trigger a grief response. Family members can therefore experience grief throughout the illness (Lord, unpublished thesis). However, very little is mentioned about grief responses in children and adolescents of a parent with young onset dementia. Davis et al. (2000) suggested grief begins when the young person accepts their parent has dementia, and realises they are losing their parent. The child will try and

maintain their attachment to their parent by looking for signs that they are still there and may search for a substitute to fulfil this important role. Robertson (1996) also found children feel unable to mourn their lost relationship with their parent and fear developing the illness.

These authors detail a number of limitations. Davis et al., (2000) question the generalisability of their findings as the children's mean age was 28 years old and over half of them had gone on to have their own children whilst Beach (1994; 1997) recognised her small sample size. The authors indicate more studies are needed in the area, including younger children and longitudinal studies, to further our understanding of the impact of this complicated and diverse illness (Beach, 1997; Davis et al., 2000).

The Current Study

With a changing demographic and more couples having children later in life, the number of dependent children affected by a parent with dementia is likely to increase (DoH, 2009). Caregiving and lack of secure attachment base have been suggested to impact on adolescent development in families with young onset dementia (Beach, 1994; Robertson, 1996; Beach, 1997; Davies et al., 2000; Szinovacz, 2003; Allen, Oyebode & Allen, 2009) however our current understanding is limited and there have been no studies which have looked at the ongoing impact of having a parent with young onset dementia.

The following study addressed this by building on research by Allen, Oyebode & Allen (2009). The original study explored the impact of having a father with young onset dementia on the four major psychosocial needs of children and young people (i.e. need for love and security, new experiences, praise and recognition and responsibility) which are considered for normal development within 'good enough' parenting (Kelmer Pringle, 1986; Reder & Lucey, 1995). The authors suggested a model of "One Day at a Time" which reflected the children's perceptions of how they coped. Children of a parent with young onset dementia have stresses comparable to spouses of individuals who develop dementia in later life, and the model drew parallels with the Pearlin, Mullan, Semple and Skaff (1990) stress-burden model of caregiving. Echoing the previous studies, they also found adolescent descriptions of being drawn into the family rather than opportunities to develop their own independence. Grief had begun to emerge with young people describing the loss of their "real father" although stress and coping were the salient themes. Longitudinal studies were recommended due to the

unique progression of dementia and the potential ongoing impact. Therefore the present study aimed to generate further understanding and theory by answering the following principal research question:

What are a young person's experiences of the ongoing psychosocial impact of having grown up with a father who has young onset dementia?

Method

Design

Since the aim was to explore the continuing psychosocial impact of having a father with young onset dementia, a qualitative methodology was adopted. Following the original study, a constructivist perspective was taken whereby a proposed theory is based on the participant's subjective reality and aims to reflect their experiences (Charmaz, 2000).

Experiences were elicited through semi-structured interviews between the young person and the researcher. Data were gathered, analysed and presented using the Grounded Theory framework as proposed by Strauss and Corbin (1990, 1998). The aim of Grounded Theory is to propose or build on a theory which is "grounded" in the data which can explain and suggest how people will respond to a similar situation. Grounded Theory is advocated as a method of choice when there is little knowledge about an area of interest. The method is data driven with the intention of inductively drawing out a theory from the information given by the participants. However, an element of deductive analysis is included as researchers draw on literature to aid understanding and not become overwhelmed by the data (Bryant & Charmaz, 2007; Moghaddam, 2006; Willig, 2001; Charmaz, 2000).

Participants

This was a direct follow-up study to that by Allen, Oyebode and Allen (2009) and therefore participants who took part in that study, carried out in 2004/2005, were identified as the target population. These participants had been identified for inclusion in Allen et al.'s (2009) study as having a parent with young onset dementia who they were living with or with whom they had a lot of involvement. They had been recruited nationally. All 12 participants (from 7 families) from the previous study were contacted and seven agreed to be re-

interviewed (See Table 1; Family identification letters have been used across both studies. Pseudonyms have only been used in the current study). Two of the fathers (from Family C and Family F) had died since the last study and the fathers of the remaining participants had moved into care. Thus all except the young person from Family F whose father did not go into care spoke about the impact of institutionalisation on their lives and the four young people whose father had died also talked about the impact of their father's death on their transition into adulthood.

Interview Guide

The interview guide was developed on the basis of the themes drawn up from the previous study, and additional lines of exploration about attachment, resilience and stress-burden (see Appendix B for Allen et al., themes and Appendix C for Interview Guide). Following, Strauss and Corbin's (1998) Grounded Theory approach the following topic areas were explored: overall effects of young onset dementia on the young person, relationships and attachment, transition into adulthood and resilience. Examples of potential opening questions on these topics included: "What have been the effects of your father's young onset dementia on you, do you think?" and "I wonder if you could tell me a little bit about your relationship with your father/ mother/ siblings?" If the father had died, additional questions exploring how they had responded to this were asked. If the young person brought in other relevant topics, these were also explored and then incorporated into further interviews, for example, young people's fears for themselves having dementia when they are older.

Procedure

Once ethical approval was obtained (see Appendix A), the previous participants were contacted by Dr Jacqui Allen, the original interviewer who enquired in writing about whether they would like to take part in the study (see Appendix D). Information about the study and an opt-in request were included in the invitation pack (See Appendices E and F). Participants who consented to take part were then approached by the current researcher to arrange an interview. Interviews took place at the young person's choice of venue.

All young people requested to be interviewed at their home. All were able to give consent without parental involvement and were aware of the aims of the study and their right

to withdraw (See Appendix G). Interviews ranged in length from 60 to 120 minutes except one interview which lasted 20 minutes. In the latter case, the interviewee requested to end the interview as the subject matter was too difficult but chose to have the data from their short interview included in the study. All participants were given the option of additional support if needed. The author made notes about the interviews immediately after each, recording her thoughts about the process.

The interviews were audio-recorded and transcribed verbatim by the researcher. Pauses and “you know” were transcribed although non-verbal communication was not. All data were anonymised. Transcripts were then analysed using Grounded Theory.

Analysis

Analysis followed Strauss and Corbin’s (1998) methodology. Each transcript was taken in turn. A label was given to each unit of meaning, often a sentence, which best summarised or represented it (open coding). Similar initial codes across transcripts were then grouped together into focussed codes (see Appendix H for example). Data were regrouped and reconsidered as new focussed codes emerged from the transcripts. Focussed codes were further collapsed or altered as the model developed through discussions with co and independent researchers. Focussed codes were then grouped into categories which also altered during ongoing discussions. The data were constantly compared until all were analysed and any new data were accommodated within the identified categories without introduction of any categories. Extensive memos were completed throughout the analysis (Detailed analysis is provided in Appendix I).

Following analysis, four main categories emerged (grief and loss, constant adaptation, feeling stuck and meaning-making) which the researchers observed ran along two continuums that crossed over each other due to the amount of linkage. These crossovers were identified by the researchers as processes and the categories were collapsed into the following: Coping (grief & loss and constant adaptation), Grieving (grief & loss and feeling stuck), Questioning (feeling stuck and meaning making) and Growing (meaning making and constant adaptation). Two themes or core categories were identified: ‘The Journey’ which gave an overall framework of how the young people told their stories and ‘Turning Points’ which suggested significant events in the journey, for example, becoming distressed when their father entered a

Table 1: Participant Demographics

P	Pseudonym	Family	Gender	Age at 1st study	Age	Age of Father*	Type of Dementia	Duration of Dementia	Family configuration 1st study	Family configuration 2nd study
1	David	D	Male	23	28	65	AD**	9 years	Lived with both parents	Lives with partner. Mother nearby. Father in carehome
2	Jane	A	Female	17	22	61	FTD***	8 years	Lived with mother. Father lived in a care home (17 months)	Lives with mother, father in care home
3	Sheena	G	Female	20	25	63	FTD	9 years	Lived with both parents	Lives alone. Mother nearby. Father in carehome
4	Nicholas	C	Male	13	17	65	AD/FTD	5 years	Lived with mother, older sister & brother. Father in care home (within last week)	Father had died in 2005. Lives with mother and older brother
5	Lucy	F	Female	20	24	56	Vascular dementia	3-4 years	Lives with both parents and younger brother and older sister	Father had died December 2008. Living at home
6	Victoria	C	Female	16	20	65	AD/FTD	5 years	Lived with mother, older & younger brothers. Father in care home (within last week)	Father had died in 2005. Currently at university
7	Jonathan	C	Male	18	23	65	AD/FTD	5 years	Lived with mother, younger sister, & brother. Father in a care home (within last week)	Father had died in 2005. Lives with mother and younger brother

* Age of father at time of interview or of death

** Alzheimer's disease

*** Frontotemporal Dementia

care home. See Table 2. Following development of the model, the author compared the categories and model obtained at the first research interviews, 4-5 years previously with the current data.

The similarities and differences were discussed with the original authors (current co-researchers) to gain some understanding of the young people's experiences over time. Thus although, the themes, categories, model and quotes are drawn from the current study, a comparison is also made with the first study. Based on this, some tentative suggestions are made about the impact over time on the lives of the participants.

Trustworthiness

To increase rigour in qualitative research, the researcher must be mindful of ensuring the suggested theory accurately reflects the data, is understandable and useful, and could be reproduced in a similar sample (Hall & Callery, 2001).

To aid trustworthiness, data were initially analysed independently by the researcher and two clinical psychologists who were supervising the research (see details below). The authors then met on a regular basis to discuss the emerging themes, discussing discrepancies and meanings until some consensus was achieved. Ideas in the meetings were recorded by the chief investigator and incorporated into the analysis (See Appendix J).

As a step to try and ensure the Grounded Theory would be understandable and useful, the tentative model was then presented to a special interest group of Clinical Psychologists who work with older people. This group understood the model and found it plausible and helpful to understanding. They stated that it followed a "natural progression" from the original study. Ideas which had value were used to expand and further develop the model (see Appendix K).

Grounded Theory usually advocates recruiting participants until new ideas have been exhausted and all data can be incorporated into the developed categories. As the current research is a follow up study, this was not possible. However, the researcher observed that new data from later interviews were incorporated into the already existing categories and this suggests that theoretical saturation may have been close.

Table 2. Processes and Process Categories (dominant emotions associated with each process in capitals)

Processes	Process Sub-Categories
Coping	<ul style="list-style-type: none"> ▪ Constant adaptation ▪ Stress and strain ▪ The illness ▪ Stepping up ▪ Coping ▪ Support ▪ TIRED ▪ BLOCKED EMOTIONS
Grieving	<ul style="list-style-type: none"> ▪ Yearning ▪ Role models ▪ Loss of real father ▪ Gender ▪ Feeling stuck ▪ Isolation and stigma ▪ REGRET/ SADNESS
Questioning	<ul style="list-style-type: none"> ▪ Ambiguity ▪ Meaning Making ▪ Future ▪ Grief and loss ▪ GUILT / SADNESS
Growing	<ul style="list-style-type: none"> ▪ Meaning making, benefit finding and identity change ▪ Connecting with dad ▪ Relationship with well parent ▪ LOVE

Reflexivity

When undertaking a qualitative study, it is important for researchers to be aware of and highlight their own influences, as this increase the likelihood of the findings accurately reflecting their participant's experiences (Hall & Callery, 2001). To this end, the researcher made field notes and memos of her thoughts and ideas throughout the analysis. Ongoing reflection with the supervisors was also utilised (See Appendix L). The researcher also asked each young person if there was anything that they had wanted to discuss which had not been asked about. This aimed to address the potential power imbalance by enabling the young person to direct the content.

The researcher is aware that initially she was more drawn to the transcripts which had had openly emotive interviews but realised later that emotive language had also been conveyed in other transcripts but their style of coping with distress and loss had masked the level of this at interview.

Furthermore, discussions with a Clinical Child Psychologist highlighted the emphasis in the thinking of the researcher and her supervisors on young onset dementia rather than adolescent transitions; this is acknowledged as having some influence on the model that is drawn out of the findings.

Results

The proposed Grounded Theory is based on the current cross-sectional data and aims to illustrate the continuing impact for children of having a father with young onset dementia. The theory is depicted through a model of how young people are affected and respond over time to their situation, with this being conceptualised as 'a journey' (see Figure 1). As the young person makes their transition into adulthood, they are simultaneously observing their father's cognitive and physical deterioration, which occurs over a long time period. The journey is depicted by two interweaving circles running around the outside of the model; the young person's journey and their perception of their father's 'journey'. Arrows indicate their journey's direction. It is suggested that the young people experience four different processes over their journey: Coping, Grieving, Questioning and Growing. The researchers suggest the young people do not experience the processes in a stage like fashion but move between them depending on where they are within their father's illness trajectory, demands on the young

person or the occurrence of a significant ‘turning point’. Evidence for The Journey and Turning Points will be presented first. Then each process will be taken in turn, describing the sub-process categories and offering supporting quotes. In each section, the categories emerging from this study are compared with those derived from the interviews with the participants at their first research interviews 4-5 years ago, in order to draw out some understanding of changes over time. Further discussion around the model will then be given.

The Journey

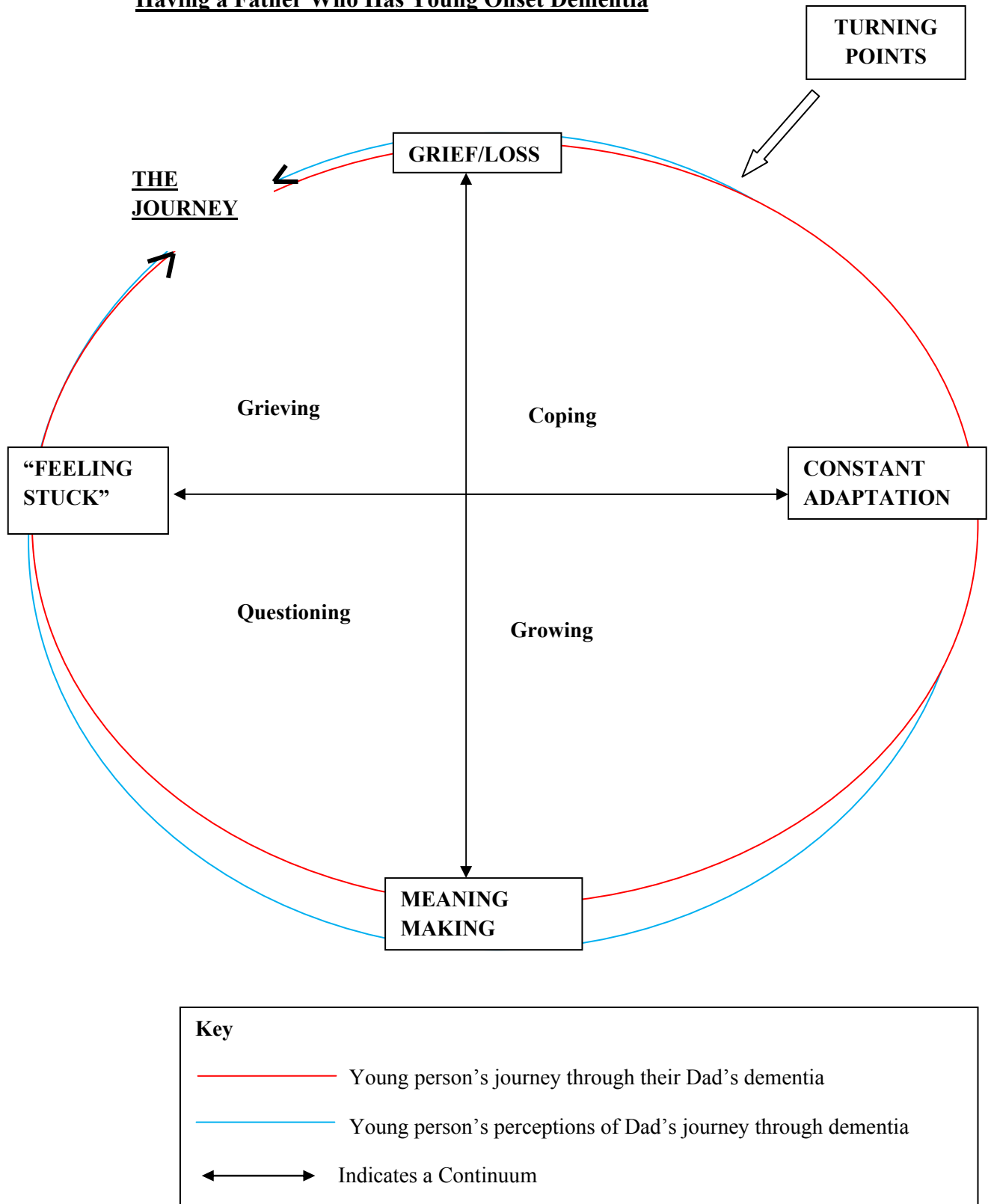
The journey was agreed by the researchers to be a metaphor that reflects young people’s descriptions of the ongoing impact of their fathers’ young onset dementia on their transition into adulthood, whilst also capturing the parallel process of watching their father deteriorate. One distinctive feature of dementia is the nature of its progression. The young people spoke about their difficulty in making sense of the regression of their father, especially as it occurred whilst they were growing up.

*I suppose it’s like having a baby almost in the house. So, rather than Dad looking after us, we were having to look after Dad. But I always think my dad had quite a lot of dignity? I didn’t think it was very nice, and I know he never would want us to be doing something like that, like cleaning up his mess. **Victoria***

These intertwined journeys are indicated in the model by the overlapping circles around the model and are described by one young person below:

*“It’s just an emotional rollercoaster constantly..... You discover like new ways to talk to him as well when you go and visit.You’re born and then you’re in diapers and then once you hit a certain age you are back in like the diapers again. It’s like Cos you know that, huh, I don’t even call him Dad half the time it’s XXX. Erm, like, you speak to him like he’s a three year old or something. And, you know where you speak to like a child and you’ve got a smile on your face? It’s like a positive thing. You do that with them and.. It’s really developing the whole relationship constantly because you deal with the different stages they move into, so you’re constantly adapting”. **Jane***

Figure 1: Constant Adaptation: The Emotional Roller-coaster of Having a Father Who Has Young Onset Dementia



Davis et al. (2000) suggested in their study that the constant redefining of a parent is one of the most difficult tasks young people face. As not only is the young person at a time when they are exploring their own identity, they are simultaneously faced with trying to understand the changes in their father.

Thus this disrupts the modelling that the father might have provided for his adolescent child. The progressive nature of dementia also threatens the attachment bond that the young people have with their father prior to his death. This has been found in adult literature to trigger grieving (Lord, unpublished thesis) and was found in our study. The emotional rollercoaster was mentioned throughout the young people's accounts and reflects how the young people felt buffered around by the different emotions over the processes.

Turning Points

Turning points were hypothesised as events that triggered the young person to move between processes and an emotional response. The authors reflected that the turning points, which can occur at any point within the journey, reminded them of a pebble being thrown into a pond (model) with the ripples being a metaphor for the effects of the turning point (pebble). Salient turning points included: diagnosis, stopping medication, care home placement and death. Sheena, for example, talks about the impact of anti-dementia medication being stopped and the way it moved her father into a different phase of illness and thus the whole family into a different stage of coping.

I don't think I would have ever put him on the Aricept and I don't know if I would ever recommend it to anyone either. when he got taken off it, the dramatic drop in how he was, you just kind of think, great, you got a kind of stable level for two or three years and then all of a sudden he's just gone. It just really was such an emotional rollercoaster for Mum and I suppose all of us to see the difference that a tablet can do

Sheena

Further turning points are illustrated below by Jonathan who talk about the impact of their father being moved into a home and the overwhelming grief experienced by Lucy when her father had to go into hospital.

That was really bad like. Because usually only really old people go into the homes. Like grandparents and that. Erm, and he wasn't that old, and we visited him once a week and things got so bad in the home; like he couldn't move, he couldn't talk and stuff **Jonathan**

Then there were the visits in and out of hospital. That just really killed me **Lucy**

Similar impact of transitions has also been noted in the adult dementia bereavement literature (Ott, Sanders & Kelber, 2007).

Processes

The model suggests that the young people move around 4 processes (coping, grieving, questioning and growing) over the course of their journey. Each process will now be taken in turn and quotes supporting that process will be offered. The processes and sub-processes are summarised in table 2.

Coping.

This process echoes the themes found in the original study, when the young people spoke of feeling overwhelmed by caring responsibilities. When asked to describe how life had been for them since their previous interview, most found it easier to give a chronological history of their experiences, beginning with the initial changes that they had noticed in their father.

They described the need to constantly adapt to the changes that occurred and of being tired and having a need to block emotions in order to continue assisting the well parent in care giving tasks. Yet they also talked about 'stepping up' to take on responsibility. A sense of lack of support from their wider family and friends was also spoken of.

Strain and stress of the illness.

As in the original study, the young people spoke about how caring and worrying about their father created a lot of fear and stress for the family. This had continued to impact on their lives and had got progressively harder as their father deteriorated further. Victoria

describes the stress and its ramifications graphically as she talks of the impact for the whole family of managing her father's restless nights.

*So like you would be lying in bed and the burglar alarm would be going off like every five minutes. So in the end we had to take turns in like erm someone sitting up at night in his room and like just trying to keep him in his room. To stop him from like doing the light switches and to stop him from doing the burglar alarm. So it ended up getting quite hard because obviously Mum had a full-time job, she had to still support all of us, so like she moved onto another bedroom and we like tried to do it between the three of us so that she could carry on like with work. And erm, I remember like it was quite hard because I'd be like missing quite a lot of days off school where I was so tired, all night like waiting up and looking after him that I just couldn't get up in the mornings to go to school. **Victoria***

Increased strain was felt when the young person was unable to meet their father's needs as he/she did not have the resources but there was no one available to help.

*He'd set off up the stairs and then fall down, all the way down the stairs which was really scary because if I was in on my own, I couldn't pick him up because he was a full grown man. And I'd just like panic and get really upset because I couldn't get him up off the floor... (Crying)... And just hurting himself. And he bashed his head and I remember one time he [...] all the stairs and he fell on the banister and bashed his head, and there was like blood everywhere. And there was only me and XXX in and I just remember panicking, thinking "I don't know what to do" because I can't get him up and he was like bleeding really bad. So that's what it was like, getting really hard. Because like I knew I couldn't look after him because he was just too big. **Victoria***

Allen et al., (2009) found that deterioration of their father to a point that the family felt no longer able to cope, coupled with increasing concerns for the health of the well parent, might precede a decision for more formalised caregiving or Care Home placement. This was also mentioned in the current study. One young person said to her mother:

"Do you want to leave your children behind as well? Because this could kill you in a whole different way, this stress" because she's got quite high blood pressure and

cholesterol. She went to the doctors and went on blood pressure tablets and I just said "It's time for Dad to go in a home". **Sheena**

Although fears for the health of the well parent had reduced at the point of the second interviews, the young people expressed a continuing sense of duty to support their well parent, as in Jane's account of her intention to go on living at home from a sense of responsibility for her mother's well-being:

I don't want to move out until I know she's either found someone or like... don't know got a companion or someone she can go out with. It's... it's looking ahead to the bigger steps.. erm, no matter how much I want to I won't leave her. **Jane**

Or Sheena's account where her mum's wellbeing was her main priority:

I've always kind of been "Is Mum ok? What's she doing? Does she need me?" **Sheena**

Stepping up.

The young people reflected that they were aware they had had to grow up quickly and had taken on adult responsibilities. Which included being involved in physical and medical care tasks, providing support to the well parent and protecting their father from others: *I don't want him to be like an animal on show.Just feels like he's an animal on show when you let someone else go and see him.* **Jane.** Jane's account speaks openly of the sense of prematurely becoming an adult:

Dealing with social services, you're doing different things you never think you're going to have to do. . . I don't know, it's kind of like roles reversed. . .I did spend more time on the phone trying to sort out dad's stuff out . . .When did I suddenly become an adult? **Jane**

Whilst Jonathan's account also shows his sense of stepping up to become the "man of the house" in his father's absence:

I thought, like that's the way I thought I should behave. Just because I'm a young male I suppose. And because I suppose because I was the oldest of the three of us as well... **Jonathan**

Lucy's story illustrates the change in the relationship with her father:

*Because the roles are kind of reversed now, whereas I used to be a baby myself. I needed looking after, feeding and everything and then Dad needs this, an older person in your life needs this now. **Lucy***

Coping.

Coping with all aspects of their father's illness was difficult for the young people. They spoke of recognising that they had a number of coping strategies which had developed during the illness and for some, since the death of their father. Similar to the original study, young people gave examples of emotion-focused and problem-focused coping. However, more appraisal-focused methods of coping were identified in the second study. Some of the appraisals suggest that the young people were attempting to make sense of their experiences. The young people spoke about "facing the illness": *You've got to drill it in your head that you know he's going to be like that. So, there's no way out of it, so you just got to face it basically. **David***; or blocking emotions so that they would be able to continue functioning:

*As for the emotional side I try to stop it a lot because... I think if I let myself go I'd need a whole week off work. And I don't want, I just don't think Dad would be, "Get a grip! Come on XXX get a grip!" So I don't really get too upset. **Sheena***

The young people recognised in retrospect that some of their initial coping strategies were sometimes maladaptive, such as excessive drinking, avoidance and pretence: *I suppose I pretended I was tough, tougher than I actually was. And then that, I probably convinced myself and that helped me get through it **Jonathan***. Subsequently, as they had got older, they spoke of employing more appropriate strategies.

Support.

Feelings of support were mixed for the young people. Most felt that their extended family and friends were not overly supportive either emotionally or practically, although one young woman spoke of the strength she gained from her faith and another young woman felt her friends were her main support. One young person spoke of how people did not truly want to know how she felt:

But then when you talk to people and you've got people saying 'Open up, tell me how you're feeling' and you tell them things like that, they're like...er... and all you turn around and say is "Well you said you wanted to know, I told you" so, you sort of learn your rings of people you can tell or. .who you don't talk to. Jane

When comparing the original and current studies, the high impact of caring for their father can be seen in the large number of sub-categories for this process in both studies.

Grieving.

Grief was observed during the original study, however it emerged more strongly in the current study. The young people made reference to the chronic nature of the illness and how it was like "*reading a really long book*" **Jane** and how "*..... [they were] going to have to watch [their father] get worse and worse and more and more downhill*" **Lucy**. Some of the young people, described feeling stuck in their grieving which they felt was like a 'never-ending story'.

Yearning.

Grief responses such as yearning were evident in the young people's accounts. Yearning took on many forms including longing for a connection with their dad, as when Nicholas says: *Like when I hear my dad's friends doing stuff with them makes me... wish he was still here* **Nicholas**. They also yearned for the past, missed teaching, missed opportunities and their future.

I still get it occasionally now, erm, if I come round from sleep too quick, I can still hear him pottering around down here and things like that. It's like eight years on and you're sort of slapping yourself here, "What the hell are you thinking?" It's not the same Jane

Yearning for a connection with their father occurred both prior to and after the death of their father. Some of the young people described yearning for their lost childhood due to 'stepping up', and now felt that their life had no purpose, with this leaving them struggling with their identity, as when Nicholas states: *[I] missed out on something. Missed out on being a teenager.* **Nicholas**

Role models.

Yearning for their dad as a positive male role model was described by most of the young people. Dads were described as “doers” who would teach the young people skills, guide them and provide structure. These functions were missed by both sons and daughters. Other males who could provide a role model were sought after and when they were found, they were valued.

*.. I think sometimes it'd just be nice to have a male like father figure in my life too, not guide me but.. give me some direction. Erm, next door neighbour, when Dad got took away, sort of took it on, that he's the one that gives me the bollocking. I'd go round and tell him I'd done something. "What the hell did you do that for?" He'd proper, like sometimes he'd made me cry, and it's just like "Yeah, ok Dad" He takes it on and he'll do it. It is just you want someone to, don't know, things like **Jane***

Loss of real father.

The young people in this study spoke of starting to lose their real dad from the moment that the illness set in. This was very much evident within the first study. The young people appeared to grieve the losses around having a father ‘in name’ but not in person:

*It was like from the beginning of the illness his past memory changed so it wasn't even like he was my real Dad. **Nicholas***

*It's, it's really hard but.. it's not, it's not like I haven't had a dad since he's died, I've not had a dad for like years obviously, because he wasn't really my dad, well he was my dad, but not himself for years so it wasn't the same dad as my dad. **Victoria***

Gender.

Two of the three young males suggested that losing their father had had a bigger impact on them than their sister because they and their father were the same gender. Jonathan's description is peppered with the word ‘male’, showing how important this is to him:

I think it was, it's harder the fact that I didn't have a male role model because I haven't got, both my granddads died before I was born and I've got one uncle, but he's useless really. He's not interested in us at all. We never see him. So yeah I think it would have been better if I had had a male role model to look up to from the male side of things **Jonathan**

I definitely think it's affected me and my brother differently to my sister. I suppose I think probably it's been harder for me and my brother **Jonathan**

Whilst Nicholas spoke of his sense of needing to take on the male role within the household once his father and brother had left home, there was also a sense of missed opportunities because his father had not been able to teach him male orientated skills.

I don't know, like, it's just like, if he wasn't here then I'd have to be like the man of the house sort of thing. Like if someone, I don't know like, tried to break in or something then I don't know.... and..... and my best mate Stuart erm, he's erm becoming a referee because he's like, he's been refereeing with his dad since he was like thirteen or something. And he took a course in it and he's got really good at it and could probably make career out of it because he's a really high level now. And I haven't done anything like that with a dad, I mean **Nicholas**

However, daughters also spoke about how losing a father had impacted on their upbringing.

I haven't got the father figure anymore **Victoria**

And I've got a lot more male friends than, than, I wouldn't say more than female friends, but I have got a lot of male friends around me. Just because I think you can learn from, from, from men.... I think that's what I really really missed, that male role-model. **Sheena**

Currently little is understood about the impact on the child of the gender of the parent with dementia. It would be beneficial for future research to look into the impact of losing a mother with young onset dementia on daughters.

Feeling stuck.

This sub-category describes the sense that a number of young people conveyed of putting their life on hold when they were more active in their father's care. Some described a sense of frustration that implied that they felt held back: *It's got to the stage now that you just wanna move on with your life* **Jane**. Feeling stuck provoked a yearning for escape and for lost childhood and a loss of control over their immediate future. The impact on their future appeared to be influenced by their age, the stage of their father's illness/death and their level of involvement.

I felt like I couldn't get out of it because I was quite young and I couldn't afford to move out, and I couldn't afford, I wasn't even working properly and it, I just felt like I'm stuck, because I can't go anywhere, I can't move anywhere and I'm just going to have to put up with it. **David**

One young person described that even though her father was in a care home, she could not make plans for her future as she wanted to remain available should anything happen. Ambivalent feelings about her situation appeared to cause distress for her as she felt unable to move on whilst her father was still alive.

But then you feel bad because you're wanting it to be over... but on the other hand if it's over.. what's going to refill that void? You've suddenly got everything you've done forever like x,y,z, to suddenly you've got no Home to go and visit, no Home to go and pay for.. and he's gone and it's like (laugh) it's not, huh, easier than you having to think of all that, and you're like.. from the moment he left I had to take on everything.. I mean like DIY, things like that, erm.. the garden, the little things, like, he'd done. And it was just like, it's such a shock to the system but once you start doing it and like eight years later.. erm.. you're not really further forward, but you're not any further back, you're just stuck.. **Jane**

Similarities here with the young people's themes in the original research indicate the high level of involvement the young people had in caring for their father and the tremendous impact their father's illness has had on their upbringing and opportunities for self development.

Isolation and Stigma.

The number of losses and grief experienced was further exacerbated by a sense of isolation. Some of this was due to participants feeling that others were not interested or could not understand: *No-one else will really question stuff, they'd just say "are you alright?" "Yeah yeah I'm fine"* **Sheena**. In addition, some of the young people felt that they needed to hide their father's condition to avoid being stigmatised.

While he was living at home it changed it because I didn't, I didn't have the guts to bring any girl back because I didn't want them to see my dad because I thought it would put them off me because they'd think I had a normal, normal family and normal parents. Because yeah so it did, it did affect my relationships while he was at home

Jonathan

In summary, Allen et al., (2009) reported the development of grief which they suggested was being delayed either because of the stigma or shame surrounding the illness or possibly due to being overwhelmed by the situation and their responsibilities. In the second study, grieving was acknowledged as the young person realised the extent of the changes that had occurred in their father and their lost experiences. It seems that as the illness progresses and the immediate demands placed on the young person decrease; grief comes to the forefront.

Questioning.

This process relates to the participants' accounts of their attempts to make sense of their father's situation and the questions this raised for themselves in relation to their fathers, in relation to their own identity and in relation to the future.

Ambiguity and meaning making.

When the young people told their stories, they spoke of their initial disbelief that the changes in their father were permanent or were going to get worse.

I remember my mum coming home one day and just being like "He's not, he's never going to get better. He's just going to get worse." So that was, at that point I just

thought it was just an illness and he's going to recover. I always had it in my head that he's not dying, he's fine and he'll come out of it eventually. **Victoria**

As the illness progressed, the young people reported the “*mad stories*” which would happen and how they would become upset and frustrated because they “[*didn't*] know what [*they*] were going to get **Lucy**. For some of the young people, the changes in their father had been explained by a professional:

[I] used to get really frustrated, like “Why won't you answer us?” I remember XXX told us that ... just like he can't help it because he's like trapped inside this body, and like as much as he wants to like answer you and he's trying, his body won't let him.

Victoria

The interviews with the three young people whose father was still alive highlighted the uncertainty around whether their father was still present. One young person described the joy and hope she felt whenever she thought she might see a sign that her father was still there:

I will see him one day and he will know who I am and I suppose that's what I hold on to, but when I go and see him he doesn't know. And you can be “Dad, Dad” and smiling. **Sheena.**

Others conveyed a sense of longing for their father to return to his former self, alongside sadness at the knowledge that this was not possible. This yearning for their dad to return was very difficult for the young people and seemed to lead to a search for meaning. Some tried to search for the meaning of why their father had become ill: *Have I done something wrong or is this some sort of punishment that God wants to take my dad away or something? You know, I never listened to my parents when I was younger and so on.* **Lucy,** Whereas others questioned their own identity and tried to make sense of who they were:

Well as you get older your emotions change and your like whole aspect changes. So.. where I was when I like, it all first started to now, like relationships, that sort of thing it's weird to sort of look back and think “Oh my god, what have I done? What have I achieved? Where have I gone? Do I actually want to stay on this path?” **Jane**

Future.

For the majority of the young people, living with dementia had led to fears for their own future and had made them consider whether they would want to start a family. One young person indicated that she was not even able to think about the possibility of having dementia in the future. The young people also described not wanting to put others through what they had been through.

“Yeah like it’s quite scary to think that I could get it and so like, oh, if I had a son I wouldn’t want him to go through all this. I’d feel like I’d ruined my son’s life if it happened to me, you know, what my dad got. Nicholas

“I’m going to end up in a nuthouse, not knowing anyone.” Cos the thought for me, it was like family and stuff. I don’t want to have a family if I know I’m going to pass the gene because I don’t want to put them through this, what I’m having to go through now. Jane

In summary, ambiguity was reported in the original study during the early stages of the illness when the young people noticed changes in their father’s behaviour and had difficulty in obtaining a diagnosis. This study showed that they continued to experience high levels of uncertainty at different points across the illness trajectory. In addition to the uncertainty surrounding their father, some of the young people had been left questioning their own identity and had fears for their own future families.

Growing.

The most noticeable difference between the Grounded Theory derived from the first study and that in the second study was the emergence of a prominent theme of personal growth. Identity Change, Finding Benefit from the experience and Continuing Bonds were mentioned by most of the young people. Love captured the overall emotion for this process. Most of the young people reported that they had grown closer to their well parent and had a better relationship with them.

Meaning Making, Benefit-Finding and Identity Change.

The young people gave a number of rich descriptions about growth. One young woman talked about her sense of thinking that there is a good reason for everything: *I think that everything happens for a reason (.....) because I think that God has got a plan for everything.* **Sheena.** For Sheena, the idea that this has given her greater empathy to help others in tough times was viewed as a great benefit: *Yeah, if anything, it's not a waste is it then? It's not a waste of my dad being ill, if I can just help someone through a situation.* **Sheena** and this was echoed by Victoria who expressed a greater immersion in life as well as greater empathy:

Although losing someone is a really really hard thing, maybe in a way some good can come out of it because like for example you might appreciate things in life more. You can be more sensitive to other people in any sort of similar situation whatsoever. **Victoria**

Some of the young people spoke of a change in their sense of themselves as a result of their experiences which they felt had turned them into more pleasant or stronger people:

There are some things that I, ah, actually think are good like that I think I don't know ... maturing more... I think it's made me a nicer person because I can understand if other people go through something similar. I think that I could understand more. **Nicholas**

I think I'm stronger because there's like, smaller things that might upset someone that wouldn't upset me now because I think like it's not worth getting upset about because like there's a lot worse things that go on and that people have to deal with **Victoria**

However, it is possible to experience elements of growth and still be searching for meaning from a loss. This is reflected in the youngest person who recognised that he had become more compassionate towards others but was still trying to make sense of the impact of his father's illness on his own identity.

Connecting with dad.

Most of the young people described an ongoing connection with their father. One young person whose father had died since the last interview described how a phenomenon on her photos, combined with something her father had said, made her feel he was still in contact with her and her family in a very special way:

*Also just after he died I remember erm, we were taking, me, my mum, my brother and some of my friends were taking photos of each other, like before a night out and erm, like my dad would always say, you might find this strange but my dad had always said "If I ever, well when I die, like if there's any way to get in contact with you I will try my hardest." and erm, I remember we were like taking photos and it happened for quite a while, but it doesn't happen anymore but it happened for about a year, whenever there was a photo of one of us, like one of the kids, me, XXX or XXX in one of the photos, like if there was a photo of just a friend on their own it would just be normal, but if it was a photo with one of us included in the photo there's be orbs all round us. There was, it was quite a nice feeling. **Victoria***

Another participant spoke of feeling she had been able to fulfil his father's role in a way that her father would have approved of:

*I'd like to think, well Dad would be proud of where I've got to on my own, erm, and that's all I think. I always think, well I've not done anything to; I've done everything I think my dad would have done for my mum. So almost kind of stood in my dad's shoes and supported Mum and I will continue to do that. **Sheena***

Growth and continuing bonds with their father were clearly evident in the young people's descriptions and from the young person's point of view these reflect positive outcomes and pride in their development.

Discussion

Four processes (coping, grieving, questioning and growing) were identified which reflected the young people's accounts of living with and being bereaved of a father with young onset dementia. The young people appear to travel through a parallel process of making sense of their own identity and maturation whilst simultaneously trying to understand the regression in their father. This is coupled with coping with the demands placed on them due to living with dementia and the grief experienced due to the number of losses they face over the illness trajectory and death.

In Allen et al.'s original study (2009), the authors proposed a model with a core category of 'One Day at a Time'. This reflected the young people's attempts to cope with the additional demands which had been asked of them. It was proposed that it had some parallels with Pearlin et al.'s Model of Stress-Burden (Pearlin, Mullan, Semple and Skaff, 1990). This was also reflected in the current study in which the young people's accounts suggest that they had taken on the identity of "young carers". "Young carers can be defined as children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent ... has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision". (p.25, Becker, 2000, as cited in Becker, 2007; 2005). The term is included here as all of the young people had been involved in caring for their father from a very young age.

The young people articulated their awareness of the role reversal and their feeling that they were becoming like a parent, as they looked after their father. Parentification has been researched across a number of areas in which a child takes on responsibility for caring for a parent and several theories have been put forward on its impact. Stein, Riedel, and Rotheram-Boras (1999) found that a young person's level of emotional distress was associated with the severity of their parent's illness and their subsequent involvement in adult role taking. This seemed to be illustrated in both studies with the young person not only caring for the father but also feeling responsible for the well-being of their mother. Studies on young carers have found adolescents can be at risk of a number of negative outcomes including poor well-being and they can experience difficulties in their transition into adulthood (Becker, 2005; 2007). In studies on young onset dementia, this seems to be further exacerbated by the sense of isolation and lack of support that the young people experienced. Stigma around dementia is well recognised in the adult literature which can leave the families feeling isolated (Allen et al., 2009; Sanders, Ott, Kelber & Noonan, 2008; Doka, 2004) whilst adolescents tend to shy away from friends who have been affected by illness for fear of catching it or becoming overwhelmed by emotions (Christ, Siegel, & Christ, 2002).

Grieving had begun to emerge within Allen et al., study although the dominant theme was coping. However, it seems from comparing the categories with adult dementia

caregiving findings that in the first study the young people may have been either trying to delay, deny or did not recognise that they were grieving due to their heavy involvement in caregiving. This continued for some into the current study. Due to the chronicity of the illness, delaying or denying grief has been suggested as a potentially adaptive coping strategy in early dementia that may enable the carer to be able to continue caregiving without becoming overwhelmed (Marwit, Meuser & Sanders, 2004). This was seen in the current study, such as in the young person who said that in retrospect he can see that he “pretended” he was tough to cope with the demands placed on him.

However, for some of the young people, the losses and subsequent grief they were experiencing over the course of the illness such as the loss of their “real father” had not been recognised by those around them. Doka (2004) suggests this may be because grieving before the death of someone may not be considered appropriate. This is known as Disenfranchised Grief and may explain why grief has been less prominent or explicit in previous studies. Disenfranchised grief appeared to further increase the sense of isolation that some of the young people felt.

The adult dementia caregiving literature clearly demonstrates that multiple losses are experienced by caregivers over the illness trajectory and grief may be triggered at any point. This was also illustrated in this study, as captured in the notion of turning points. Becoming young carers, as well as potential trigger points for grief, places the young people in a very vulnerable position for which they may not have adequate resources. Possibly due to the length of caregiving, the young people appeared to become stuck in the coping process when the demands for “stepping up” and support were intense. This seemed to be towards the early part of the illness when the ill parent was at home and may have been exacerbated by a perceived lack of familial and external support for the family. This finding has some resonance with Earley and Cushway’s theory (2002) of the impact of caregiving on children which suggests that excessive burden which is outside their competence, can lead to a sense of failure that remains in adulthood. However, whilst our study reflects the notion of young carers carrying burden beyond their current capacity, it does not support the idea of the young people necessarily carrying a continuing sense of failure into their adult lives.

As well as taking on a caring role, children of a parent with dementia are also faced with the uncertainty about whether the “essence” of their parent, or as the young people

described their “real father”, remains. As dementia progresses, the psychological being of the person becomes increasingly damaged, ultimately leading to “social death” before a person dies. This progression is unique. Uncertainty about a loss or death is known as Ambiguous Loss (Dupuis, 2002 Silverberg, 2007; Blieszner, Roberto, Wilcox, Barham and Winston, 2007). It has been found to generate high distress and can trigger a grief reaction. To regain some control, making sense of the situation is common. This can be seen in the young people’s accounts as they spoke of frustration, uncertainty and distress in the changes observed in the father and their attempts to make sense of this. Due to the unpredictable nature of dementia, uncertainty over whether the person still remains can occur over the whole trajectory, leaving the young person oscillating between a state of turmoil and trying to resolve the ambiguity, as could be seen in the young people’s descriptions of “connections” with their father and accounts for why things had happened. Successful meaning making has been associated with well being, however if a person is not able to make sense of the loss or becomes stuck in unresolved meaning making, they may experience grieving for a long period (Bonanno, Wortman & Nesse, 2004).

In addition to questioning their father’s identity, the young people also gave rich descriptions on how living with and being bereaved of a father with young onset dementia had impacted on their wellbeing and identity. The young people spoke of missing out on a positive male role model and seeking out replacements to fulfil this important role. One young person wondered whether he and his brother were more affected by this than a girl would be. Young males have been suggested as being overlooked as carers by peers and social services (Eley, 2004) and therefore may have an unmet need for someone to understand their lack of a father figure. However, opportunities for development appeared reduced for all the young people. Previous research has found that reduced opportunities to observe role models can affect an adolescent’s identity formation (Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009; Davis et al., 2000) and the accounts of the young people in this study do seem to reflect a struggle to find identity that was affected by the loss of the male parent and taking on a caring role.

For one of the young people whose father had died, he spoke of feeling lost without his father and no longer felt a sense of purpose in his life as he had no guide. He often felt overwhelmed with sadness and yearning for his father’s presence. Although yearning is a part

of grieving, this young person was in a lot of distress and his account was suggestive of a complicated grief reaction (Neimeyer, Baldwin & Gillies, 2006) which prompted the researcher to offer additional help. The young person accepted. Another young person had also sought additional help prior to interview as she described the impact caring for her father had had on her sense of identity.

For some of the young people, they had gone on to internalise the essence of their father which provided them a sense of comfort and protection. Having a connection from which the person finds comfort and benefit is known as a 'continuing bond' (Klass, Silverman & Nickman, 1996; Klass, 1999; Attig, 2000; Field, Gao & Paderna, 2005). People's continued bond can be through using the person as a role model, feeling their comforting presence in times of stress or doing things for them, such as one young person who had taken up a musical instrument because his father had wanted his children to learn to play (Neimeyer, Baldwin & Gillies, 2006). Normand, Silverman and Nickman (1996 as cited in Gillies & Neimeyer, 2006) provide support for continuing bonds in children who had lost a parent. However, if a young person has not made sense of their death, a strong attachment to their deceased parent may heighten their distress as opposed to providing comfort (Gillies & Neimeyer, 2006).

Living with dementia had also impacted on young people's thoughts for the future. Fears of getting the disease themselves is noted in children of cancer sufferers and adult children of parents with dementia (Wong et al., 2009; Jarvik & Blaser, 2005). However, notably different, are young people's fears of putting their children through the ordeal which they had been through. This may suggest that due to the demands and losses experienced over the illness trajectory make this one of the hardest illnesses to contend with.

However, although a number of negative consequences had been indicated by the young people, they also gave accounts of growth and pride emerging from their experiences. A number of different perspectives (cognitive, trauma, attachment and constructivist) have suggested that there can be personal growth following bereavement, as indicated by making sense of a death, finding benefit in the experience or undergoing identity change. This results in the integration of new meaning into a person's existing meaning structures (Gillies & Neimeyer, 2006; Neimeyer, Baldwin & Gillies, 2006).

Growth has been described as becoming as more compassionate towards others, more forgiving and more tolerant of themselves and others (Hogan and Schmidt, 2002). These can be related to intrapersonal development as a person becomes more resilient, independent and confident, as well as an increased appreciation for life, changes in life priorities and interpersonal changes, such as improvements in relationships with families (p.192, Milam, Ritt-Olson, Unger, 2004). This process has been increasingly researched within the bereavement literature and has been associated with better psychological outcomes (Gillies & Neimeyer, 2006; Helgeson, Reynolds, & Tomich, 2006; Neimeyer, Baldwin & Gillies, 2006). Several studies support the notion of adversarial growth in adolescents (Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009; Neimeyer, Mehta, Harrison, & Currier, 2008; Milam, Ritt-Olson, Unger, 2004; Aldwin & Sutton, 1998; Oltjenbruns, 1991).

However, the relationship between distress and growth is unclear and some studies have shown that growth and depression can occur simultaneously whilst others have found no relationship between the two. Evidence suggests that they are distinct concepts (Milam, Ritt-Olson, Unger, 2004; Gillies & Neimeyer, 2006) and this was also found within our study.

Summary and Conclusions

This paper proposes a Grounded Theory to account for the impact on young people of having and subsequently being bereaved of a father with young onset dementia. The theory is depicted through a model of how young people are affected and respond over time to their situation, with this being conceptualised as ‘a journey’. Four different processes (coping, grieving, questioning and growing) were identified between which the young person moves. The proposed Grounded Theory describes an interplay between stress-burden and grief processes. Integrating these perspectives into one model seems plausible and parallels recent work by Noyes et al. (2009), who have recently suggested an integrated model of stress and grief for adults’ caregiving in dementia.

As identified in the original study, there is evidence to suggest that young people experience stresses that are similar to those reported by spouses who are caring for an older partner with dementia. Descriptions of grief had begun to emerge in the previous study however they became more prevalent in the young people’s current stories, reflecting their later position within the dementia journey. The researchers suggest the young people’s

accounts show that they use meaning-making to adapt to the losses experienced whilst living with a parent with dementia as well as the response to the death of their loved one.

Some of the young people had experienced the death of their father since their last interview. Parental death has been suggested as one of the most traumatic events which can happen in childhood. Death of a parent has been linked with a range of negative outcomes (Haine, Ayers, Sandler, & Wolchik, 2008) and it is possible that with the early onset of psychological erosion of the person and with care duties, the young person may be at risk of a similar range of negative outcomes (depression, anxiety, grief, lower self esteem and greater external locus of control) prior to the death of the parent.

Although parallels have been drawn with parental terminal illness literature, there are certain aspects of the young person's experiences of young onset dementia which appear to be distinct from experiences of other terminal illnesses. One of the main differences is the contrast between the young person's growth into adulthood whilst, at the same time, they perceive watching their father regress into childhood, thus losing their father's ability to provide a role model. This, along with the long drawn out period of ambiguous loss of their father that affects the sense of security of the attachment base, hinders the usual trajectory of transition of these young people from childhood into adulthood.

However, growth, benefit finding, identity change and continuing bonds were not raised in the initial interview guide yet were spontaneously talked about by the young people and in great length. These spontaneously raised themes provide strong evidence that despite the stress and distress of this period in their lives posttraumatic growth may eventually occur in the lives of these young people.

Clinical implications

Young people are often not the primary focus of services provided to families where someone has dementia. However, although they are not the primary caregivers, our studies suggest that the young people are heavily involved with caregiving tasks and consequently either block their emotional responses to be able to function, do not recognise their emotional response as grief or their grief is disenfranchised (Doka, 2004). When demands lessen, grief may emerge, which can be at any point in the illness trajectory or after death. Therefore

interventions need to consider both the stress-burden and grief, including the impact of ambiguous loss and the impact this may have on their own identity formation.

In order to address some of the ambiguity and uncertainty, young people should also be offered potential opportunities to explore and understand the nature of dementia, their own responses and how it has impacted on their own identity.

Care should be taken to validate the young person's emotional responses as often their grief is disenfranchised. Interventions for young people who have lost a parent suggest that it is important to decrease the number of stressors which the child experiences and increase resources to deal with the stressors. This can be done both before and after the death has occurred. Psycho-education is offered as one of the main interventions with emphasis on understanding the process and their possible feeling of lack of control (Haine et al., 2008). Neimeyer et al., (2006) also suggest there is a growing evidence base for narrative therapies in assisting individuals in making sense of loss and the way these young people told their stories suggests this would be a helpful therapeutic approach.

Advantages, Limitations and Future Directions

This study has a number of limitations. Only 7 of the original 12 participants agreed to be re-interviewed. Therefore the sample is small and it is possible that those who were not interviewed may have had different experiences. Furthermore, only one of the children of British Asian origin agreed to be re-interviewed. However, the young person's account contributed fully to the proposed model and did not highlight any cultural differences.

Three of the young people who agreed to be re-interviewed were from the same family (Family C) and their father had passed away shortly after the initial interviews were conducted in 2005. Furthermore, the father of another participant had also died two years prior to the interview and the fathers of the other 3 participants were now in care. This means that the accounts given in the current study are not so much about the current experience of living with a father with dementia, but are about the ongoing impact of *having* lived with a father with dementia, being separated from that father and subsequently, for some of the sample, experiencing his death and its aftermath. As illustrated above, the authors observed that the young people would describe their 'journey' in detail from the beginning and offered a very rich retrospective account of their transition into adulthood against the impact of this

changing backdrop. The depth of the accounts suggests that the study remains helpful in understanding the impact of having a parent with young onset dementia on transition to adulthood, even when a component of that account relates to response to the father's death.

Limitations which were noted for the original study are also relevant for this study. Gender differences and traditional role models were revealed in the young people's accounts, with the young males questioning whether they had been more affected than their sister. However, our study was limited by the fact that only those with a father who was affected took part. Studies including young people whose mothers have dementia are needed to explore potential gender differences further. Also since the young people within the current study now have a mean age of 23 (range 17-28), further studies with younger children are necessary to establish whether the model holds true across a younger age group.

In true Grounded Theory research, the researcher would continue to recruit until categories were exhausted. This was not possible in the current study, however as there have been no longitudinal studies conducted with this population, the study remains worthwhile.

Despite these shortcomings, this is currently the only study to re-interview young people about the ongoing impact of having a father with young onset dementia. The in-depth interviews gave a rich and detailed insight into the young people's transition into adulthood and have furthered our understanding of the lives of these young people.

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PUBLIC DOMAIN BRIEFING PAPER

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**THE CONTINUED IMPACT OF YOUNG ONSET DEMENTIA ON
DEPENDENT CHILDREN AS THEY MAKE THE TRANSITION INTO
ADULTHOOD –**

A FOLLOW UP STUDY TO ALLEN, OYEBODE AND ALLEN (2009)

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PUBLIC DOMAIN BRIEFING PAPER

The Continued Impact of Young Onset Dementia on Dependent Children as They Make the Transition into Adulthood - A Follow up Study to Allen, Oyebode and Allen (2009)

Natasha D. Lord

This research was carried out as part of the requirement for the Clinical Psychology Doctorate (Clin.Psy.D) at Birmingham University. Supervision was provided by Dr Jan Oyebode at the University of Birmingham. Supervision was also provided by Dr Joanne Allen, Consultant Clinical Psychologist at the Birmingham Working Age Dementia Service, and Dr Jacqui Allen, Clinical Child Psychologist at South Devon Healthcare NHS Foundation Trust, who conducted the original research.

Overview

The research component is comprised of two parts: the empirical paper and the literature review. The literature review explored what was already known about how individuals, specifically a spouse or adult child, grieve whilst caregiving for a person with dementia up to and including their death. Research suggests that relatives experience multiple losses and grief over the course of caring for someone with dementia; with some differences between men and women, and between adult-child and spouse caregivers. Duration of disease and transitions have also been found to affect caregivers' grief responses. Throughout the course of looking after a relative with dementia, particular events are more likely to trigger a grief reaction; for example, spouses have been found to experience high levels of distress when their partner is placed into a carehome. Grieving prior to death appears to be more akin to "true grief" rather than anticipated grieving for a future death. A number of indicators for future research and interventions are offered. Services should consider intervening as early as possible such as at diagnosis, conduct regular assessments of grief throughout a person's illness, as well as provide psycho-educational and support groups for caregivers and family counselling (Sanders, Butcher, Swails & Power, 2009; Sanders, Ott, Kelber, & Noonan, 2008; Sanders, Morano & Corley, 2003; Sanders & Corley, 2003 Holley & Mast, 2009; Boerner, Horowitz & Schulz, 2004; Dupuis, 2002; Robinson, Clare & Evans, 2005; Meuser & Marwit, 2001.)

The empirical paper adopted a qualitative design using a Grounded Theory Approach as proposed by Strauss and Corbin, (1998) to answer the following question “What are a young person's experiences of the ongoing psychosocial impact of having grown-up with a father who has young onset dementia?” The study was a continuation of Allen, Oyeboode and Allen’s (2009) Having a father with young onset dementia: The impact on well being of young people. Ethical approval was gained from Central Manchester Research Ethics Committee on 17th June 2009.

Background

Although more people are likely to get dementia in later life, there are a significant number of people who will develop dementia under the age of 65 years old. The Alzheimer’s Society (2007) suggests that there are over 18,000 people under the age of 65 who have dementia in the UK alone. Identifying this population is important as the needs of people with young onset dementia and their families have been found to be different from individuals who develop dementia in later life and very little is known about the impact on dependent children who have a parent with young onset dementia (DoH, 2008; Mather, 2006; Beattie, Daker-White, Gilliard, & Means, 2002). Only 6 studies have been published over the past 13 years which have included young children who have a parent with young onset dementia (Beach, 1996; Robertson, 1996; Beach, 1997; Davies, Clovis, Ingram, Priddy, & Tinklenberg, 2000; Szinovacz, 2003 and Allen, Oyeboode & Allen, 2009). These studies have found that children of a parent with young onset dementia are greatly affected with the stresses of supporting their well parent comparable to the stresses experienced by spouses looking after an older partner with dementia. Grief following loss of their relationship with their parent, feeling unable to mourn their loss and fears for their own future were also identified but have not been explored in detail. However, Davies et al., (2000) recognised the mean age of the children in their study was high (28 years old) and only Allen et al., (2009) specifically looked at children with a parent of young onset dementia. Furthermore, all studies were cross-sectional. Recommendations were made for studies to include younger children and for longitudinal studies to build up a more comprehensive picture. Allen et al., (2009) addressed the first criticism by interviewing 12 young people aged between 13 and 24 years old (mean age 19) who had a father with young onset dementia. They found that young children were heavily involved in looking after their father and coped by taking it “one day at a time”. The

current study addressed the second criticism by re-interviewing the young people identified in Allen et al., (2009) study about their ongoing experiences of having a father with young onset dementia.

Method

Since this was a direct follow up to Allen et al., (2009) study, the twelve young people (from seven families) who were interviewed 4-5 years previously were identified as the sample population. In the first study, all young people had a father with young onset dementia whom they were living with or whom they were heavily involved with. The young people were sent an invitation pack to partake in the study by Dr Jacqui Allen. Seven of the young people agreed to be re-interviewed about their continued experiences of having a father with young onset dementia. For two families (four young people), their father had died between the studies. The fathers who were still alive were all living in carehomes and were visited by the young people. Interviews took place at the venue chosen by the young person and last approximately an hour and a half. All interviews were transcribed verbatim and analysed using Grounded Theory (Strauss & Corbin, 1998). Grounded theory is a qualitative methodology proposed when there is little known about an area of interest and aims to build a theory which is firmly rooted in the data given by the participants.

Findings

Young people's experiences of having a father with dementia are complex, occur over a long period of time and are unique to other types of terminal illness such as cancer whereby the parent remains psychologically available to the child prior to death. A model of how young people are affected and respond over time to their situation, with this being conceptualised as 'a journey' is given. As the young person makes their transition into adulthood, they are simultaneously observing their father's cognitive and physical deterioration from dementia which they attempt to make sense of and adapt to. Grief is felt from the numerous losses which are experienced throughout the illness. However, the majority of young people described growing from their experiences of having a father with young onset dementia. It is proposed that the young people move through 4 processes over the course of their father's illness and death; Coping, Grieving, Questioning and Growing. These processes do not occur linearly but are triggered by their age, the stage of the illness

and salient events in the journey, for example, ceasing anti-dementia medication. For some young people they described becoming confused about their own identity as they appeared to have taken on a “carer identity”. For the majority of the young people, they spoke of feeling isolated from others who do not understand their situation and therefore are coping alone. A continuing connection with their father was heard in all the young people’s accounts. However, the young people’s accounts suggest that despite the stress and distress of this period in their lives posttraumatic growth may eventually occur in the lives.


Clinical Implications and Future Research

Young people experience both strain and grief whilst helping to look after their father with young onset dementia. Due to their developmental stage and demands placed on them, young people may be in a very vulnerable position which they may not have adequate resources for. There is also potential that due to the number of losses experienced over the journey, the young people may experience grief during the illness which may not be recognised by those around them as it is not considered appropriate to grieve whilst someone is still alive. The young person may have difficulty understanding their response and feel socially isolated. Questions about their own identity may also occur. Therefore services should also consider the needs of children in Working Age Dementia Services. Future research would aim to build on the findings of these studies by conducting more research on younger children who are re-interviewed over regular time periods to develop a more comprehensive picture.

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Further contacts

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APPENDICES

LITERATURE REVIEW

APPENDIX A:

INSTRUCTIONS TO AUTHORS FOR LITERATURE REVIEW

APPENDICES

EMPERICAL PAPER

APPENDIX A:

ETHICAL CLEARANCE CONFIRMATION

APPENDIX B:

ALLEN, OYEBODE & ALLEN (2009) THEMES

Allen, Ovebode & Allen (2009) Themes

<i>Main Categories</i>	<i>Sub-categories</i>
Damage of Dementia	<ul style="list-style-type: none">• Change in behaviour• Lack of diagnosis• Difficult behaviour• Father's safety• Understanding about Dementia
Reconfiguration of Relationships	<ul style="list-style-type: none">• Loss of 'real father'• Change of family role• Parentification
Strain	<ul style="list-style-type: none">• Physical strain• Psychological strain• Stigma• Worry about well parent
Caring	<ul style="list-style-type: none">• Sharing the care• Lack of help from relatives• Going into care
Coping	<ul style="list-style-type: none">• Problem focused• Emotion focused

APPENDIX C:

INTERVIEW GUIDE

PROPOSED INTERVIEW GUIDE

Below are four areas of interest to ask participants. The following is a framework to facilitate conversation around the young person's experiences of living with a father with younger onset dementia, however if salient themes arise during interview, these will be followed up. The young people will be made aware that interviews will follow their life story and is not a question and answer session.

Overall Effect of Younger Onset Dementia

1. What have been the effects of your father's younger onset dementia on you, do you think?
2. How might things have been different if he had not developed younger onset dementia?
3. Has your parent's younger onset dementia affected other areas of your life? How have they been affected? What do you think would be different about your life?

Transition into Adulthood

4. I wonder what you feel has been the impact that your father having YOD has had on you as a person?

Supplementary considerations

- If the young person's father has moved into care or died, then explore how this has impacted on their view of themselves as a person.

Relationships/ Attachment

5. I wonder if you could tell me a little bit about how your relationship with your father/ mother/ siblings? Do you feel that your relationships have changed in any way?

Supplementary considerations

- If the young person's father has moved into care, then explore the impact of this on their relationship using prompts and open questions.
- If the young person's father has died, then allow the young person to talk about this, how they responded to it and how it has affected their life.

Resilience

6. How have you coped with your father having YOD?
7. What have you had to do in the family home? Can you try me about changes which have happened in the family home over the past couple of years?
8. Has the progression of the illness been as you would have expected?

Amended version, 15th May 2009

APPENDIX D:

INVITATION LETTER

Date:

Reference number:

Dear

Study title – The Continued Impact of Young Onset Dementia on Dependent Children As They Make The Transition Into Adulthood - A Follow Up Study to Allen (2004/2005)

Four years ago, I contacted you to ask if you would be willing to share your views and thoughts of having a parent with younger onset dementia. Thank you for agreeing to take part in the research, your contribution was extremely valuable and has helped our services to understand what young people may be worried about and how their lives may have been changed since their parent developed younger onset dementia.

I am writing to you again to ask if you would be willing to take part in a follow-on study. We currently have no information about the longer term impact of growing up with a father with younger onset dementia. It would be valuable for us to learn about this from your experiences. We appreciate that much may have changed since you last spoke with me. It is possible that you may have moved away from home that your father is no longer living at home or even that your father may have died. Whatever your situation, we would still like to hear about your experiences if you are willing to talk with us.

So you can decide if this is something that you would like to continue with, please read the enclosed information booklet and discuss it with anyone if you wish to. If you need more information or have any questions, please let me know.

I will contact you in a few days to ask if you would like to take part in the research. If you think that you might like to take part in the study, I will give your details to Natasha Crisp, Trainee Clinical Psychologist, who will then contact you to explain the research in more detail.

Yours sincerely,

Dr Jacqui Allen,
Clinical Psychologist

APPENDIX E:

INFORMATION ABOUT STUDY

The Continued Impact of Young Onset Dementia on Dependent Children As They Make the Transition into Adulthood - A Follow up Study to Allen (2004/2005)

Invitation paragraph

About 4 years ago, you took part in a research interview with Jacqui Allen, about your experiences of living with your dad who had younger onset dementia. We appreciate that many things may have changed since then, and we are now writing to ask if you would be willing to opt in to be re-interviewed. We wonder how things have changed and how having a father with younger onset dementia may have impacted on your life. It is possible that you may have moved away from home that your father is no longer living at home or even that your father may have died. Whatever your situation, we would still like to hear about your experiences if you are willing to talk with us.

Before deciding if you would like to, it is important that you know why we are asking you. Please read the following and discuss it with someone if you wish. If you are unsure about anything or would like some more information, you can call Natasha Crisp on [REDACTED] who will be happy to answer any questions.

Natasha Crisp is a Trainee Clinical Psychologist who would like to ask you some questions about how things may have changed for you since you were last visited by Jacqui Allen. Jacqui came to visit you in 2004 to talk with you Thank you.

What is the purpose of the study?

We have only just started to appreciate what it is like for young people who have a parent with dementia and we know very little about the ongoing impact for a young person over time. The purpose of this new research study is for us to find out more about this.

Why have I been chosen?

You have been chosen because you have spoken previously to Jacqui Allen about your views and thoughts about having a father with younger onset dementia and how you have coped. We would like to know how you think and feel about things now.

Do I have to take part?

It's your choice whether or not you want to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide at any time that you don't want to take part, you can stop without giving any reason. If you do not want to take part or change your mind, this will not affect the level of service that you or your father might be receiving. If any at time you need to have a break, just let us know. Your well-being is really important to us.

What will happen to me if I take part?

Natasha will come and visit you at a suitable place of your choice. She will ask you about your life over the last 4 years since you last meet with Jacqui Allen in 2004.

What do I have to do if I want to take part?

Ring Jacqui who will pass your details onto Natasha or post your response in the self addressed envelope that has been provided with the information sheet. Natasha will then ring to arrange a time to come and visit you at home or wherever is most comfortable for you. You will be asked to sign a consent form. She will be interested in hearing about how things have been since you last saw Jacqui in 2004. This meeting will last 1 to 2 hours. It is important that you feel that you have enough time to talk about the experiences that you want to.

What are the possible disadvantages and risks of taking part?

What you talk about with Natasha may be upsetting. If you feel upset at any time, you can take a break or you can stop the interview whenever you want as your well-being is important to us. Natasha will be able to offer information about support groups if you would like to know about these

What are the possible benefits of taking part?

Jacqui learnt a lot from you before about what it is like for young people who have a father with younger onset dementia. By learning how life has changed and how a young person copes with those changes over time, we (NHS services for people with younger onset dementia) may be able to find ways that we can help and support young people as they go through these changes.

What happens when the research study stops?

A summary of the research will be shared with you and with services for younger onset dementia and we hope it may also be published in leading journals for dementia care.

Will my taking part in the study be kept confidential?

Your consent form will be kept separate from the interview that you give. The interview will have all names and addresses changed so that you cannot be recognised from it. Only you, Jacqui and Natasha will know that you have taken part in the research. If Natasha became seriously concerned about your welfare in the interview, she would advise you that she will need to speak to her supervisor about asking for further help.

Contact Details:

If you need to contact Natasha, please use the details below. If Natasha is not available, please leave a message and she will get back to you as soon as possible.

Natasha Crisp
University of Birmingham
Edgbaston
B15 2TT
Tel no: [REDACTED]
Email: [REDACTED]

APPENDIX F:

OPT-IN LETTER

Opt- in Letter

I would like to opt-in to be re-interviewed about my experiences of having a dad with younger onset dementia

☐

I agree to be contacted by Natasha Crisp to discuss the study further and arrange an interview if I am still happy to carry on.

☐

Please provide your contact telephone number and address for Natasha to contact you.

Signed:

Young person

Date

APPENDIX G:

CONSENT FORM

CONSENT FORM

Title of Project: The Continued Impact of Young Onset Dementia on Dependent Children As They Make the Transition into Adulthood - A Follow up Study to Allen (2004/2005)

Name of Researcher: Natasha Crisp, Trainee Clinical Psychologist

Please place your initials in the box

I confirm that I have read and understand the information sheet (version 3) for the above study.

☐

I understand that I am free to withdraw at any time, without giving any reason and my withdrawal/refusal to participate in this study will not affect the level of service that I might be receiving.

☐

I agree to have my interview recorded and for Natasha to use quotes of what I say in her report as long as my data is anonymised.

☐

I would like to receive a summary of the research when it is completed

☐

I agree to allow Natasha to access the transcripts of the original interview

☐

I agree to take part in the above study.

☐

Name of young person

Date

Signature

Researcher

Date

Signature

APPENDIX H:

EXAMPLE OF INITIAL CODES INTO FOCUSSED CODES

<p><u>Sense making (of self/ illness)</u></p> <p>Keeping connection with dad Dad keeps us hanging on Why? Uncertainty? Who am I? Where am I? Where do I belong? Recognition???? Waiting/not waiting death Challenge from God Physical strength Wouldn't want to be alive like that Not a waste of being ill Noticing changes before diagnosis Travelling/ getting things out of system Religion Medication Everything happens for a reason He'd be happier not here Treating the wrong thing (ambiguity) Dad's death? I think he got things in his head that he couldn't let go Something good can come out of it Understanding the "stepping up" Baby – looking after Something good/ something bad</p>	<p><u>Coping</u></p> <p>Dad knew it was best Sick DSH Alcohol Denial Escape/forgetting Routine Support Bolting Well parent Defended I can do it alone/myself Channelling emotions Cycle of caring/process Counselling "strong" Fend for yourself Relating to others (common ground) "what would dad say??" Not in touch with emotions Don't access friends group He'd be happier not here</p>	<p>Acting tough Don't allow tears Pretending Helping / doing Music Religion Happy thoughts Includes coping with the future (future) Accepting Justifying (you could see it, you know) Not going to die Comparison with other illnesses He'll remember the good bits with you Detached Don't think about it Blocked Family priority Doing something for dad – uni – (connection) "that my life now" Didn't want to believe it Time Preparing self for death</p>
<p><u>Role reversal/ stepping up (parenting)</u></p> <p>Baby Cycle Childlike proper care Put others first Expectations Take on dad's role Becoming dad Responsibility Adapting self Become protector (well and ill parent) Hiding emotions Relationship with well parent Mum priority Family priority Worrying about well parent Priorities change – stay at home with family Financial implications No pressure on well parent Have to be independent Do things myself</p>	<p><u>Turning points</u></p> <p>Carehomes Tablets Death Breaking point Diagnosis Planning funeral Carehome experience Not walking Noticing things Not my dad When he doesn't recognise you Stopped talking/interaction "he's never going to get any better"</p>	

APPENDIX I:

DETAILED ANALYSIS

[REDACTED]

[REDACTED]

Further Detailed Analysis

Initially 4 main categories were drawn from the data; Meaning Making, Constant Adaptation, Grief and Loss, and Feelings. These included all the focussed codes which had been generated. Two overarching themes were also identified: The Journey and Turning Points which interwove throughout the categories. See table below.

Category	Focussed Code
<u>Meaning Making</u>	<ul style="list-style-type: none">▪ Sense making▪ Making sense of how coped? Instead of coping▪ Relationship with others▪ Why I think I needed a role model??▪ Growing▪ Feeling stuck▪ Before and after the illness▪ Gender
<u>Constant Adaption</u>	<ul style="list-style-type: none">▪ Coping▪ Support▪ Isolation▪ The illness▪ Relationship with well parent▪ Strain and stress▪ Control and power▪ Role reversal
<u>Grief and Loss</u>	<ul style="list-style-type: none">▪ Ambiguous illness▪ Carehome experience▪ Connecting with dad▪ Events▪ Yearning▪ Real dad▪ Missing Role model?▪ Dad time▪ Loss▪ Never ending process▪ Physical changes▪ Personal sacrifice
<u>Feelings</u>	
<u>Turning Points</u>	
<u>The journey</u>	

However as the process continued and the model started to develop, a fifth category, “Feeling Stuck” then emerged. Feeling stuck developed as the authors saw that the young people’s perception of their experiences appeared to be on a continuum as they oscillated between adapting to the illness to feeling incapacitated by what was happening (between Constant Adaptation and Feeling Stuck). A second continuum also emerged from the data reflecting the young people’s grief. The researchers suggested that the young people alternated between being overwhelmed by their feelings of loss to trying to make sense of what was occurring (Grief and Loss and Meaning Making). The Feelings category was subsequently collapsed over the 4 categories within the model as different emotions appeared to fit different processes See table below.

Category	Focussed Code
<u>Meaning Making</u>	<ul style="list-style-type: none"> ▪ Sense making ▪ Making sense of how coped ▪ Relationship with others ▪ Why I think I needed a role model ▪ Growing ▪ Before and after the illness ▪ Gender
<u>Constant Adaption</u>	<ul style="list-style-type: none"> ▪ Coping ▪ Support ▪ The illness ▪ Relationship with well parent ▪ Strain and stress ▪ Role reversal
<u>Grief and Loss</u>	<ul style="list-style-type: none"> ▪ Ambiguous illness ▪ Carehome experience ▪ Connecting with dad ▪ Real dad ▪ Missing Role model ▪ Waiting for death ▪ Dad time ▪ Loss ▪ Never ending process ▪ Physical changes ▪ Personal sacrifice ▪ Anticipatory grieving
<u>“Feeling Stuck”</u>	<ul style="list-style-type: none"> ▪ Future ▪ Events ▪ Yearning ▪ Control and power ▪ Isolation ▪ Feeling stuck
<u>Themes:</u> <u>The journey</u> <u>Turning Points</u>	

APPENDIX J:

**EXAMPLE OF MINUTES FROM MEETINGS WITH CO-RESEARCHERS
(REFLEXIVITY)**

From: Natasha Lord
Sent: 22 February 2010 13:55
To: Natasha Lord; Allen Joanne; Jacqui Allen
Cc: Jan Oyebode
Subject: Initial Codes

Hi All,

Following a meeting between myself, Jan and Jo on Friday whereby we had a conversation around the initial codes that I had come up with. Please find attached a copy and suggested focussed code titles. Any suggestions of name changes for focussed codes and areas that I have missed in the transcripts would be greatly appreciated

The conversation focussed around the following areas:

1. Keeping a connection with dad
2. Amount of love in the scripts - why is this? Dementia doesn't discriminate. Also consideration with this of: gendered ideas - do young people compensate for dad's decline by placing him into very gendered role that he excelled at? i.e. teacher/ skiller/ most intelligent person that I have ever met....
3. The differences between the young females (want to make dad proud) and males (appear to lose hope/motivation/direction) again, does this come back to gender ideas? suggested to look at this further (gender studies)

Let me know if there is anything else that you need.

Tash

APPENDIX K:

SUGGESTIONS FROM SPECIALIST INTEREST GROUP

List of Suggestions given from the Specialist Interest Group

1. To consider whether the YP consider themselves as a caregiver and they lose this identity when their father has died. Where does this leave the YP if they have not had opportunity to develop independently of their family? How do they make sense of themselves?
2. Others recalled their own experiences of having a partner who protected their ill parent from others (e.g. cancer). Maybe this occurs in others illnesses and needs to be looked into further?
3. It would be interesting to see how the YP coped/integrated the knowledge of themselves in the original study. Did they change their coping styles? Who did/not cope? How has the young person progressed over the years?
4. Is there anything about the age of the YP? During the discussions, the youngest's grief response came up and could this be different due to a development factor? How come the young person didn't try and "escape" after his dad died at 14/15 years old to start doing teenage things like his siblings had?
5. Exploring how a young person coped in the beginning. Is there continuity in their ways of adapting? Is there growth? Thoughts were driven by VICTORIA who originally drank (activity) and then restarted horse-riding to be close to her father (activity).
6. The experience of carehomes and what YP make of them - are they more caught up in how a carehome looks rather than maybe the relationship with carers? This did not appear to be the case (DAVID - angry at foreign carers, JANE would go and visit carers as well as dad).
7. Attachment model and the impact that carehomes have on YP similar to spouses because of the type of bond with their parents, primary rather than secondary as they do not have a partner/ not that stage of development?
9. Exploring further the impact of how well the well parent coped and does this appear to have influenced how the YP coped and subsequently made sense of the illness etc?

APPENDIX L:

EXAMPLE OF A MEMO

Example of a Memo – 24th February 2010

- “Just deal with it” - acceptance – dragging on – weariness – feeling stuck!
- You deal with it the best way that you can
- I am the sponge!
- SENSE MAKING
 - Of myself
 - Of my dad’s illness e.g. YP2 – Anger.
- Does stepping up stop the young person from accessing the support that they need?
- YP3 – sense of self = growth – “I do feel for others with dads who fight”
- Young people change their lives around illness – they don’t move out, give up jobs, caring...
- “relaxed into my life when mum started relaxing”
- Dad becoming child – YOUNG PEOPLE APPEAR TO TRY AND MAKE SENSE OF THIS CHANGE? OCCURS AT A TIME WHEN THEY ARE ASKING THEMSELVES ABOUT THEIR OWN IDENTITY – “do I want to stay on this path? What have I done?”
- Government taking money – AWARENESS OF ADULT ISSUES AND HELPING OUT
- Relationships as substitute male role models? Role models are extremely important to the young people – replacement dads? Is this something about where they are in their journey? Dads also provide skills and physical security.
- Future – 1. How affected life
 - 2. how affected actual future
- Stepping up – young people make important decisions about their own life based on what is happening in their well parents life e.g. financial implications
 - This includes a whole gamit of areas
- No one takes father to see dad especially if they didn’t see him before the illness!
- Young person 3 has a very long conversation with best friend about being able to rely on yourself – what exactly is being conveyed here?
- Ask for very little for themselves!
- “I wish I could just say “ I really need your help”
- GROWTH

- CHANGE
- COPING – ALL THEMES COMING THROUGH
- As it goes on, support decreases – sense of isolation because of the illness
- THE JOURNEY – ongoing, long time, lots of changes, parallel journey – theirs and watching their dads???

APPENDIX M:

INSTRUCTIONS TO AUTHORS FOR EMPIRICAL PAPER